

**‘FEELING LIKE ME AGAIN’: RECONSTRUCTING
WOMEN’S SELF-IMAGE THROUGH BREAST
RECONSTRUCTION**

Ms Lindsay McKean

**SUBMITTED IN PART FULFILMENT OF THE DEGREE
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ABSTRACT

Aims: National guidelines recommend that breast reconstruction surgery should be widely available for women undergoing mastectomy following a diagnosis of breast cancer. An examination of the relevant literature revealed a lack of theoretical conceptualisations of breast reconstruction's role regarding women's self-image. The present study aimed to explore this topic further and develop appropriate theory.

Method: A Grounded Theory methodology was employed to retrospectively explore the experiences of women who had undergone breast reconstruction, focusing upon the concept of self-image. Ten participants took part in the current study, recruited from breast cancer support groups. Data was collected by means of semi-structured interviews and analysed via the NVivo 8 computer package. The views of three breast cancer care staff were also canvassed via focus group in order to verify the findings and emerging theory.

Findings: The current investigation generated a core category entitled 'Feeling Like Me Again'. This category emerged as a reflection of the participants' belief that breast reconstruction surgery has helped them to restore a sense of normality in their lives and in how they see themselves. The core category comprised two principal categories, namely 'Normal Appearance' and 'Normal Life', and their subordinate themes. A further two main categories were generated, entitled 'Moving On' and 'Image of Sick Person'. The categories were formulated into a Model of Breast Cancer, Breast Reconstruction and Self-Image. Implications of this model in relation to existing theory and clinical practice were considered.

Conclusions: This study has highlighted that breast reconstruction's role in relation to women's self-image is subtle and wide-ranging. Further research is recommended to test and develop the model.

INTRODUCTION

In March 2008, the findings of the First Annual Report of the National Mastectomy and Breast Reconstruction Audit (MBR; NHS Information Centre, 2008) were widely reported in the national press¹. The attention received by this report demonstrated the public interest in this issue and suggests that this research project has come about at a timely juncture. The MBR Report indicated that access to breast reconstruction services following treatment for breast cancer is not uniform across the UK. This 'postcode lottery' has reportedly arisen from inequity of funding and poor communication between clinicians. However, the number of patients requiring surgery for breast cancer continues to rise every year due to increasing incidence of the disease (Cancer Research UK, 2008). When coupled with a growing demand for reconstructive options, the MBR Audit concluded this was putting considerable pressures on breast cancer services. This demand is likely to extend to psychological services also, due to their inclusion in national guidelines for the management of breast cancer (SIGN, 2005).

The focus of this study is to explore aspects of the psychological role of breast reconstruction, specifically how it may alter how women see themselves. Hence, the researcher is not directly concerned with the accessibility or effectiveness of breast cancer and reconstructive surgery services. However, findings from a study such as this, when added to the existing body of literature, may be influential in promoting a variety of issues related to breast reconstruction, including access to services and measurement of outcome.

¹ Faster Breast Reconstruction Call (BBC News, 7 March 2008). See references for web address.

BACKGROUND

Before detailing the method and findings of the present study, the background literature relevant to the topic of breast reconstruction following a diagnosis of breast cancer will be reviewed. This will begin with an overview of breast cancer and its treatment, before exploring the topic of breast reconstruction and self-image in greater depth. This chapter ends with a description of the project aims.

1.1 Breast Cancer

Breast cancer is now the most common form of cancer in the UK (Cancer Research UK, 2008)². It is also, by some distance, the most commonly occurring cancer in women, accounting for nearly 30 per cent of all cases (NHS Information Centre, 2008)³. This translates to approximately 44,000 new cases in the UK every year, with 1 in 9 women experiencing breast cancer in their lifetime. The most recent Scottish statistics available report that there were a little under 4000 new cases in 2004, accounting for 28.1 per cent of all cancers in women (ISD Scotland, 2007). This equates to a lifetime risk of 1 in 10 in Scotland.

Breast cancer predominantly affects post-menopausal women, however approximately 1 in 5 of those diagnosed with the disease is now under the age of 50 (Cancer Research UK, 2008). The development of breast cancer is linked with risk factors such as obesity and the long-term use of medications such as Hormone Replacement Therapy (HRT) and oral contraceptives. Somewhat surprisingly

² While there are more cases of non-melanoma skin cancer in the UK, this type of cancer is often left out of national statistics as it is easily treated and cured (Cancer Research UK, 2008).

³ While males can also be diagnosed with breast cancer, this study will focus upon the female experience only. The psychology of male breast cancer is discussed by Brain et al. (2006).

however, while risk is known to increase in relation to the number of first-degree relatives diagnosed with breast cancer, statistics indicate that there is no family history of the disease in eight out of nine cases (Cancer Research UK, 2008). Happily, survival rates for breast cancer patients in Scotland have increased from 64 per cent for those diagnosed in 1980-1984 to 84 per cent in 2000-2004. This improvement can be attributed to several factors, including the growth in numbers of earlier diagnosis of cancers due to screening programmes; advancement in treatment options, particularly hormonal therapy; and better delivery of patient care (ISD Scotland, 2008).

In the majority of cases, a diagnosis of breast cancer leads to a protracted period of treatment, typically involving courses of chemotherapy, radiotherapy and long-term hormone therapy. These 'adjuvant therapies', designed to destroy cancer cells and reduce the risk of future recurrence, are often preceded by surgery to remove the cancerous tissue. If the tumour or lump is relatively small, breast conserving surgery usually takes place, also called a lumpectomy. This involves removing the lump together with a minor amount of surrounding tissue, allowing the rest of the breast to be left intact.

In cases where the lump is larger, when there is more than one tumour, or when the cancer is directly beneath the nipple, it is likely that a modified radical mastectomy⁴ would be required, involving removal of one or both breasts. It is also common for some or all of the axillary lymph glands, found under the arm, to be removed, in

⁴ Hereafter referred to as 'mastectomy'.

order to minimise the chances of the cancer spreading. Despite an equivalent survival rate, it is not uncommon for women to elect for a full mastectomy even in cases where only a lumpectomy is indicated (Baron & Vaziri, 2004). It has been suggested that, in addition to fears of recurrence, women “sometimes feel that their breast has ‘betrayed’ them and they want to remove it” (Lynn, 2004; p85).

It has been reported that more than 16,000 mastectomies for breast cancer are performed each year in the UK (NHS Information Centre, 2008). Steligo (2005) describes that following this surgery, women have a choice to make regarding how they prefer to manage the resulting physical changes, i.e. loss of the breast. The first option is referred to by Steligo as ‘empty chest’, meaning that women may choose not to attempt to replace the breast, finding instead that they are able to adjust to their new body. Kasper (1995) suggests that many more women would be content with this option if it were not for the medical establishment and society’s emphasis upon regaining an ‘appropriate’ female appearance.

Alternatively, for those who feel that they prefer to have a natural breast shape and more balanced appearance, the next possibility is to use an external prosthesis, an artificial breast form which can be made out of foam, rubber or silicone, the latter being the most effective material. Some prostheses are attached to the breast wall with adhesive, others are placed inside special pockets sewn into bras or swimming costumes, for example. While this option proves to be sufficient for many women, others find that their prosthesis is uncomfortable to wear and worry that it may fall out of their clothing at inopportune moments. In an influential work, Audre Lorde

wrote about her decision following mastectomy not to use a prosthesis due to its artificiality:

"I looked strange and uneven and peculiar to myself but somehow, ever so much more myself, and therefore so much more acceptable, than I looked with that thing stuck inside my clothes. For not even the most skilful prosthesis in the world could undo that reality, or feel the way my breast had felt...". (1997; p44).

In addition, Harcourt and Rumsey (2001) note that a prosthetic breast can function as an upsetting daily reminder of the cancer and so, for many women, the distress of losing a breast cannot be ameliorated in this way. The remaining option available to women following mastectomy is to have further surgery to reconstruct the breast. This option is chosen by approximately one quarter of women undergoing mastectomy (NHS Information Centre, 2008), however there is evidence that with increased awareness and advances in surgical techniques, the demand for this service is growing (Parker, 2004; Watson, 2004).

1.2. Breast Reconstruction

1.2.1 *Surgical techniques*

Harcourt and Rumsey (2001) report that breast reconstruction surgery was first attempted in the early 20th century, however results were frequently poor. Since those days, the development of new and more successful techniques has led to the recommendation that reconstructive surgery is routinely offered to all women undergoing lumpectomy or mastectomy (NICE, 2002; SIGN, 2005). Breast reconstruction involves one or more operations to create a new breast shape. Baron

and Vaziri (2004) note that while the goal of reconstruction is ideally “to create a breast mound that is realistic in feel and appearance, ...and is symmetrical with the opposite breast” (p.90), every effort should be made to ensure that prospective patients understand the limitations of this surgery, e.g. the new breast will not have the same appearance and sensitivity as the natural breast. There are a number of different types of breast reconstruction surgery, the suitability of which is dependent upon, for example, the amount of breast tissue that has been removed and the patient’s general health, lifestyle and preferences (Breast Cancer Care, 2006).

The first main type of reconstructive surgery involves the use of breast implants. Implants filled with silicone or another fluid are placed under the skin and muscle of the chest through the original mastectomy scar, allowing additional scarring to be avoided. Where there is only a small amount of tissue remaining on the chest, an ‘expander’ implant can be used to stretch the skin gradually through regular injections of a saline solution. At the end of this process, a permanent implant is inserted. Although this is a more straightforward surgery, with a shorter recovery period, breasts reconstructed with implants can become unnaturally firm and pain can result from ‘capsular contracture’, caused by scar tissue forming around the implant (Baron & Vaziri, 2004). There is also the risk that implants may rupture or deflate through damage or normal wear and tear.

The second main type of surgery is ‘autologous’ reconstruction, whereby the breast mound is rebuilt using the patient’s own tissue. This is suitable, for example, when the patient has received radiotherapy treatment, which can affect the elasticity of the

skin and thereby rules out expansion with implants. Flaps of skin, muscle and fat are taken from another area of the body, also called the donor site. If the donor site is close to the breast area, the flap may remain attached to its original blood supply (pedicle flap). Tissue transferred from elsewhere in the body is removed with its blood supply intact (free flap), requiring complicated microsurgery to reconnect the blood vessels. Autologous reconstruction can be accomplished by taking tissue from three different areas of the body (BACUP, 1997).

A latissimus dorsi flap, also called a LAT-D or back flap, uses the large muscle that lies beneath the shoulder blade. The flap of muscle is cut away from the back, then rotated and threaded under the armpit to the chest wall, maintaining its own blood supply. Back flaps can be combined with an implant to better approximate the size of the other breast. For a transverse rectus abdominis myocutaneous flap, simply known as a TRAM flap, muscle and overlying skin is taken from the abdominal area, typically with the blood supply intact. Baron and Vaziri (2004) describe that this is the most widely used autologous procedure, as an implant is not required and results are usually aesthetically superior. Furthermore, scarring can be kept very low in the suprapubic area, whereas with a back flap, scarring is often much more visible to others.

TRAM procedures are often nicknamed as 'tummy tuck' flaps as there can be an incidental improvement in the abdominal contour, however the recovery period is lengthy and the loss of muscle can lead to weakness or hernia. In a Deep Inferior Epigastric Perforators flap, known as the DIEP flap, only abdominal skin and fat is

taken, meaning that the muscle is spared and so abdominal weakness occurs less frequently. However, the added complexity of this microvascular technique means that it is not commonly used. The last form of autologous reconstruction takes muscle, skin and fat from the buttocks. This Gluteal Free Flap again requires microvascular skills and has the longest surgery and recovery time of all the different techniques.

Autologous reconstruction is often seen as superior to the use of implants as not only is the resulting appearance and feel much more similar to a natural breast, but using the patient's own tissue avoids the potential problem of capsular contraction (Baron & Vaziri, 2004). However the surgery time for autologous reconstruction is much more extensive and results in scarring at both the donor site and the breast area. Furthermore, transferred skin may not match the colour or texture of existing skin.

After initial surgery, it is not uncommon for additional operations to be needed in order to reduce scarring or further shape the reconstructed breast. Harcourt and Rumsey (2001) describe that many women also undergo further surgery to the contra-lateral breast, such as lifting or reduction, in order to achieve a balanced appearance. Once the reconstructed breast has had sufficient time to heal and 'settle', the patient can choose to undergo nipple reconstruction also using skin tissue grafted from the other breast or the inner thigh (BACUP, 1997). A tattooing technique can also be used to effect the appearance of a nipple, but this does not provide a shape beneath clothes. All in all, breast reconstruction is a complicated, time-consuming

and sometimes painful process, necessitating the patient to be highly motivated and confident in her chosen course of action.

1.2.2 Why choose breast reconstruction?

Harcourt and Rumsey (2001) describe that women who choose to have reconstructive surgery, when compared to those who do not, often share certain characteristics. For example, they are typically married, younger in age and of higher socio-economic status. These findings are corroborated by other authors (e.g. Frierson & Andersen, 2006; Rowland et al., 2000). These demographic factors are easy enough to study, however there is more difficulty when we try to assess the role of women's individual beliefs and needs.

It is inarguable that the choice to have breast reconstruction surgery, regardless of the specific technique used, brings with it the risk of considerable physical and psychological distress (Harcourt & Rumsey, 2001). What then are the reasons that embolden women sufficiently to face this risk? Querci della Rovere (2004) and Reaby (1998) describe that practical reasons are often cited, such as being able to avoid having to use an external prosthesis. This allows a greater choice of activities to take part in (e.g. sports), of clothing to be worn and eliminates the anxiety over a prosthesis becoming loose or falling out. A number of emotional reasons for undergoing reconstructive surgery are also noted by these authors, including the need to feel feminine and sexually attractive, to have more confidence and to feel like oneself or 'whole' again. Women are also encouraged by the assurance that breast reconstruction does not restrict any follow-up treatments that may be necessary, such

as radiotherapy, nor does it prevent the detection of any recurrence of the disease (BACUP, 1997).

Regarding those women who choose not to have reconstructive surgery, researchers have suggested that the likelihood of pain and discomfort acts as a disincentive, together with the perception that reconstruction will make them appear vain (Harcourt & Rumsey, 2001). Using semi-structured interviewing with 64 participants, Reaby (1998) also found that women choosing not to undergo reconstruction do not consider it crucial to their emotional wellbeing, do not wish to have unnecessary anaesthetics for surgery and sometimes perceive themselves as 'too old' for reconstruction.

1.3 Psychological issues in breast reconstruction

1.3.1 *Psychosocial outcome of mastectomy*

Over the last 30 years, a sizeable body of evidence has been presented to highlight the possible psychological sequelae of a breast cancer diagnosis and treatment via mastectomy (e.g. Ganz et al., 1998; Goldberg et al., 1992; Harcourt et al., 2003; Morris et al., 1977). In addition to the pressure of dealing with a diagnosis of a potentially life-threatening disease, these authors have described that women's quality of life can be affected by post-operative difficulties including clinically high levels of anxiety and depression, together with a negative impact upon their body image, sexuality and social and occupational functioning (Parker, 2004). It has been

estimated that 45 per cent of early breast cancer patients experience anxiety or depression (Henson, 2002).

The phenomena of poor body image (i.e. an individual's thoughts about his/her physical appearance based on self-observation and the reactions of others) and disruption of sexual functioning have received a significant amount of attention in the literature in particular. It is posited that the breast is commonly seen as a symbol of femininity, with mastectomy thereby having a disastrous effect upon women's feelings of attractiveness (Schover, 1991). This may then result in the avoidance of looking at or touching the mastectomy site. The suggestion that women can feel disfigured or mutilated by their mastectomy is supported by studies which have consistently found that women who have breast conservation surgery (as opposed to mastectomy) have more positive feelings about their bodies (e.g. Mock, 1993; Nano et al., 2005; Rowland et al., 2000) and less sexual dysfunction as a result.

Frierson and Andersen (2006) discuss that long-term psychological distress is unlikely to occur in the 'average' breast cancer patient, but could be more likely in those undergoing radical treatment such as bilateral mastectomy. Ganz (2008) also lists a number of patient characteristics that have been identified as risk factors for psychosocial distress. Firstly, the rarity and unexpectedness of being diagnosed with breast cancer can precipitate distress in younger women, i.e. those under the age of 50. Younger women often have the additional burden of having to care for small children during their treatment, or perhaps are forced to come to terms with the realisation that they may not be able to have children due to premature menopause.

Furthermore, a considerable number of younger women may not have a spouse or partner at the time of diagnosis and treatment, leading to concerns regarding the impact their surgery may have upon starting new sexual relationships in the future. This may provide some explanation for younger women's enthusiasm for reconstructive surgery, noted earlier. Ganz (2008) also recognises that a lack of social support, both practical and emotional in nature, together with the presence of pre-existing mental health difficulties, can be predictive of difficulties with mood after diagnosis.

However, Parker (2004) describes that the majority of studies in this area have concluded that, irrespective of whether they have mastectomy or breast conserving surgery, the effect upon women's psychosocial adjustment is likely to be short-term and difficulties resolve themselves with time. It has, however, been suggested that poor body image may take longer to settle than other areas of concern (Harcourt et al., 2003). Ganz (2008) reports that, thankfully, most women are able to manage their psychological distress with the use of personally available support systems such as friends and family, as well as professional resources, e.g. breast care specialist nurses and support groups.

Lastly, Ganz (2008) describes further psychosocial concerns experienced by breast cancer patients including fear of recurrence and intrusive thoughts about illness. While it is likely that these concerns are shared by all women in the period after treatment, the extent to which each individual is affected can depend upon her ability to cope with the loss of control and adapt to facing an uncertain future.

1.3.2 Psychosocial outcome of breast reconstruction

The benefits of undergoing breast reconstruction were initially recorded only in terms of surgical success and improvement to physical appearance. As the frequency and popularity of the surgery has grown, psychosocial outcomes are also being assessed, leading to reconstruction being promoted as an action which can aid emotional recovery and well-being following treatment for breast cancer (Breast Cancer Care, 2006).

Hill and White (2008) describe that research has predominantly explored the body image and sexuality outcomes of women who undergo breast reconstruction compared to those who undergo mastectomy or lumpectomy, typically via quantitative methodologies. Some of these studies have found evidence for the beneficial effect of reconstructive surgery. In a questionnaire-based retrospective study of 577 patients in total, Al-Ghazal et al. (2000a) found that women who had reconstruction ($n = 121$), when compared to a mastectomy-only group ($n = 456$), had significantly better body image and self-esteem. Superior outcomes of body image, sexual functioning and feelings of attractiveness have also been illustrated in a range of other studies (e.g. Dean, Chetty, & Forrest, 1983; Mock, 1993; Pusic et al., 1999).

However, results contradictory to this have also been found. For example, in a quantitative study ($n = 190$), Yurek, Farrar and Andersen (2000) showed that during the immediate postoperative period, women who had mastectomy with reconstruction engaged in less sexual activity than those who had lumpectomy or mastectomy alone. Additionally, Harcourt et al. (2003) found that undergoing breast

reconstruction does not guarantee that feelings of altered body image will be diminished. It is possible that these findings may be explained by the use of a prospective study design, offering both pre- and post-operative views of women's experiences.

To add further confusion, some authors have suggested that reconstruction may contribute to an improved overall quality of life, especially when compared with women undergoing mastectomy only (Parker, 2004; Watson, 2004). For example, Al-Ghazal et al. (2000a) reported significantly less anxiety and depression in their reconstruction sample. However, the majority of research in this area has found that overall quality of life is the same with both mastectomy-only and reconstruction groups (e.g. Reaby & Hort, 1995; Rowland et al., 2000). In another prospective study, Nissen et al. (2001) examined quality of life for women who had lumpectomy, mastectomy alone, or mastectomy with reconstruction. They found significantly greater mood disturbance in women who had undergone reconstruction, with these differences remaining 18 months after surgery. It has been suggested that this somewhat unexpected result could have arisen due to women being inevitably disappointed with the results of surgery, as no reconstructed breast mound could ever have the same appearance and sensation as a real breast (Nissen et al., 2002).

The potential role of reconstructive surgery in ameliorating psychosocial distress has been countered further by the findings of Rowland et al. (2000). In a study which benefited from a sample size of 1957 breast cancer survivors, they demonstrated that one year after diagnosis, women's quality of life is more likely to be impacted upon

by her age and side effects of adjuvant therapy, rather than the surgery used. This perplexing picture also extends to research which has compared the impact of different reconstruction techniques upon psychosocial adjustment, where findings are once again inconsistent. For example, Franchelli et al. (1995) demonstrated that autologous reconstruction has better aesthetic and psychosocial outcomes, whereas Wilkins et al. (2000) found the same quality of life outcome level for women undergoing both autologous and breast implant reconstruction. Furthermore, a recent study of long-term psychosocial outcomes found that gains continued to be present two years after reconstruction, but specific procedure type had a limited effect (Atisha et al., 2008).

Watson (2004) concludes that the research has so far been unable to demonstrate any clear advantages of reconstruction over breast conservation surgery. This highlights the need for professionals in this field to be careful not to endorse breast reconstruction surgery as a “universal panacea for the emotional and psychological consequences of mastectomy” (Harcourt et al., 2003; p1060).

1.3.3 Timing of reconstructive surgery

When first developed, reconstructive surgery was always carried out in a separate operation to the original mastectomy. Leaving a delay between surgeries like this meant that any radiotherapy and/or chemotherapy would be completed prior to reconstruction and there would be time to allow greater healing of the mastectomy site. Harcourt and Rumsey (2001) describe that ‘delayed reconstruction’ was felt to be preferable not just from a medical perspective, but also from a psychological

perspective. This belief arose from research which proposed that a delay prior to surgery would provide valuable experience of living with a mastectomy. If a woman was given sufficient time to grieve for and accept the loss of her breast, it would then help the reconstructed breast to be more easily incorporated into her body image (Winder & Winder, 1985).

It is now possible however to have reconstructive surgery at the same time as the mastectomy, commonly called 'immediate reconstruction'. The popularity of this method was slow to rise, due to concerns that it could complicate adjuvant therapies or mask cancer recurrence. As these concerns have now proved unfounded (Roth et al., 2005), patients and surgeons alike are presented with a choice about the preferred timing for surgery, which has both practical and psychological implications.

Immediate reconstruction is often assumed to be preferable to a delayed procedure as it offers superior cost-effectiveness (two surgeries for the price of one) plus a speedier recovery time for the patient (Bremner-Smith et al., 1996). In a turnaround from the 'time to grieve' hypothesis presented by Winder and Winder (1985), other studies, e.g. Rowland et al. (1995) have suggested that if a woman requests immediate reconstruction, it can be seen as an indication of positive adjustment to her breast cancer diagnosis and treatment. Wellisch et al. (1985) reported that women having immediate reconstruction report less distress at the time of surgery, perhaps due to its role as a psychological 'buffer'.

Other studies have demonstrated that immediate reconstruction offers lower levels of psychological morbidity when compared to delayed reconstruction (Watson, 2004). For example, using a retrospective design, Al-Ghazal et al. (2000b) found that women who had immediate reconstruction were significantly more satisfied with their appearance, contributing to better body image and self-esteem. They were also found to experience significantly lower levels of mood disorder than women who had undergone delayed reconstruction surgery. This study offered support for the findings of Wilkins et al. (2000), who reported that women undergoing delayed surgery had poorer body image scores one year following surgery than those who had undergone immediate reconstruction. However, both these studies suffer from the methodological limitation of not having a mastectomy-only cohort for comparison.

Authors who support immediate reconstruction argue that superior outcomes are achieved through this approach as the women undergoing this surgery do not have to live with the loss of their breast (e.g. Bostwick, 1995; Dean et al., 1983; Stevens et al., 1984). However, Hill (2004) challenged that belief, suggesting instead that a loss still occurs with immediate surgery as although the shape of a breast is maintained in these instances, it is merely an approximation of the original breast, now forever removed. Further evidence has been found to suggest that immediate reconstruction may not always be preferable to its delayed counterpart. For example, Harcourt et al. (2003) demonstrated significant improvements in quality of life and psychosocial functioning, one year after surgery, for immediate and delayed groups alike. Additionally, Rowland et al. (1995) noted that women who had undergone delayed

reconstruction were more satisfied with the outcome, in terms of appearance, than those who did not wait for surgery. However, none of the participants in this study were able to choose whether they received immediate or delayed reconstruction surgery.

National guidelines (NICE, 2002; SIGN, 2005) suggest that breast reconstruction should be provided at the time of mastectomy where appropriate, i.e. when requested by the patient and when not contraindicated by other treatment. However the MBR audit has found that the proportion of immediate reconstructions being carried out has only grown by 4 per cent in the last decade (NHS Information Centre, 2008). A number of authors have expressed their concern about the time pressures placed upon women when they are considering their surgical options. For example, Roth et al. (2005) found a greater incidence of psychosocial impairment and functional disability in women who were seeking immediate reconstruction, suggesting that preoperative psychosocial distress should be examined before deciding whether to opt for immediate or delayed surgery. Furthermore, Harcourt and Rumsey (2001) warn that adequate time has to be made for the decision-making process:

“..there is a danger that women offered the choice of immediate reconstruction have less time to make informed decisions regarding surgery and that those decisions are being made whilst a woman is still reeling from the shock of diagnosis.” (p.480)

While opinion on the optimum timing for reconstruction continues to be unclear, it is recommended that further research should be carried out to examine this issue (Watson, 2004).

1.3.4 Breast reconstruction and self-image

In examining the role of breast reconstruction in the psychosocial adjustment to surgery for breast cancer, a number of terms are used to describe areas of functioning and potential change. As mentioned previously, body image is one of the most frequently studied concepts in this area, meaning “the mental image that an individual has of their physical self” (Harcourt & Rumsey, 2001; p.481). Frierson and Andersen (2006) describe that body image is a multidimensional concept and can be closely linked with other idioms such as femininity, self-confidence, attractiveness, self-esteem and sexuality. In familiarising herself with the relevant literature, the present researcher noted that some of these terms seemed to be used interchangeably, despite their different meanings. White (2000) also acknowledges that researchers in this field often use one term when in fact they are measuring another, making it very difficult to arrive at clear conclusions regarding the role that breast reconstruction plays for women.

Another descriptive term which appears perhaps less frequently throughout the literature is ‘self-image’ (e.g. Cromptvoets, 2006; Ferrario, 1998; Hart, 1996; Reaby et al., 1994). Self-image can be defined as ‘the way a person feels about his or her personality, achievements and value to society’ (Cambridge Online Dictionary, 2008). It is therefore a qualitatively different and broader concept than body image for example, as it is related to one’s whole identity and sense of worth. Lynn (2004) describes that a diagnosis of breast cancer is life-altering and affects all aspects of a woman’s life, not merely her feelings about her physical appearance. Self-image can also be seen, in this context, to encompass women’s views of themselves as an

individual, within the family, as a mother and wife perhaps, or within society in general.

Spence (1995) suggests that “..illness (is) the ultimate crisis of self-representation” (p.146). Following breast cancer surgery, the task for women then is to integrate the physical and emotional changes caused by this life-threatening disease into their image of themselves. It is indicated that some women undergoing mastectomy may be more able than others to manage this re-negotiation of identity. Schain et al. (1984) suggest that older women may rely on an inner sense of worth rather than physical attributes, providing an explanation for why reconstructive surgery is less popular in this age group. Other studies suggest that a re-negotiation of how we see ourselves may not be always necessary. Reaby et al. (1994) studied the ‘total self-image’ of women undergoing mastectomy-only surgery (n = 64) and those having breast reconstruction (n = 31), compared with a no-mastectomy control group (n = 78). No significant differences were found in self-image between the three groups, challenging the commonly held belief that mastectomy inevitably results in psychiatric morbidity and/or a change in identity.

1.4 Methodological Shortcomings of Existing Research

Harcourt and Rumsey (2001) allege that the lack of clarity regarding the psychological role of breast reconstruction over mastectomy alone is to some extent due to the methodological problems present in the existing body of research. They cite a major lack of studies with a prospective design, leading to the risk that

participants may fail to accurately depict their breast cancer surgery experiences. Retrospective studies are also subject to the effects of cognitive dissonance, whereby women “adjust their preoperative view of themselves in order to reconcile their previous and present situations” (Harcourt & Rumsey, 2001; p 483). Cognitive dissonance is identified as having influenced the findings of Reaby et al. (1994) for example, by shifting women’s perceptions of mastectomy as distressing to being seen as a positive experience instead.

It is acknowledged that outcomes of reconstruction may be affected by a wide range of confounding variables, some of which could be controlled for by adopting a randomised, controlled trial (RCT) design. However, this has rarely been possible in this field of research as it would remove patient choice with regards to surgical treatment or type of reconstruction. For example, in Dean and colleagues’ (1983) study, participants were randomised into either immediate or delayed reconstruction groups during the mastectomy operation. Authors (e.g. Harcourt & Rumsey, 2001; Wilkins et al. 2000) have questioned the ethical justification for randomisation of participants in breast reconstruction studies, describing that it risks an adverse impact upon women’s psychosocial adjustment due to having gone into the operation ‘blind’. Further considerable shortcomings common to research in this area are discussed by Guyomard et al. (2007). These include the use of small sample sizes with no power calculations and only basic statistical analysis.

Existing research into breast reconstruction has also been over-reliant upon quantitative methodologies (Harcourt & Rumsey, 2001), which are typically

designed to verify pre-existing theory. These studies often rely upon unstandardised measures from which firm conclusions cannot be drawn and the questionnaires that have been used to study women's hopes, fears and beliefs about themselves often lack the sensitivity required to study such constructs. The amount of qualitative research in this area, needed in order to explore women's thoughts and feelings in depth, is very much in the minority.

A recent study by Marshall and Kiemle (2005) employed Grounded Theory techniques upon retrospective interviews with 12 women and their partners. It highlighted the impact of breast reconstruction upon the sexual self (Marshall & Kiemle, 2005). However, other aspects of women's self-image were not addressed by this research. Another qualitative study by Kasper (1995) explored the psychosocial consequences of breast cancer with 29 women, but was presented from a staunchly feminist perspective. It therefore focused upon the role of social and cultural forces in reference to breast reconstruction. Furthermore, Hill and White (2008) conducted interviews with 10 women who had undergone the autologous TRAM flap procedure, half on an immediate reconstruction basis and the other half delayed. Using thematic analysis, their study focused upon the difficulties associated with the loss of the breast and a changing body image.

1.5 The Present Study

1.5.1 *Research Aims*

There is a growing body of research into the psychological aspects of breast reconstruction surgery, however it has so far been dominated by quantitative methodologies. This can serve to limit the depth and breadth of our knowledge regarding this phenomenon. The current research wished to generate a deeper understanding of breast reconstruction and the role it plays in women's views of themselves following treatment for breast cancer. Rather than attempting to find evidence for specific hypotheses, the researcher identified a number of general areas of investigation which it appeared were not comprehensively addressed in the existing literature. Hence, the following research aims were used to guide the study:

- How does the experience of breast reconstruction surgery affect women's views of themselves (i.e. their self-image)?
- What role does reconstruction play in addressing and overcoming the challenges of day-to-day life following a diagnosis of breast cancer?
- What role does reconstruction have to play in adjusting to breast cancer and illness experience?
- What additional meaning, if any, does breast reconstruction hold for women?

As suggested by Willig (2001), these initial research aims identify the topic under study but do not make assumptions about what may be found. In previous studies,

the term self-image has been used to refer to women's feelings about their appearance. For the purpose of this study, women's feelings about their bodies and how they believe others to perceive them, i.e. body image, is just one part of self-image.

These research aims appealed to a qualitative methodology as this approach is more naturalistic and immerses the researcher in the social world of the participants. Qualitative approaches are also suitable when only small samples are available, as in this case. In order to gather data from those who have experienced breast cancer and breast reconstruction, it is necessary to recruit from a particular group of women, limited in number. However, the use of small samples like this allows women's voices to be heard, when they otherwise might not. It was hoped that the information-rich data generated would allow the development of a theory to conceptualise the relationship between breast reconstruction and women's self-image.

METHODOLOGY

2.1 Design

2.1.1 Choice of Methodology

A qualitative research design was suited to this study as the overall goal was to explore the experiences of women who have undergone breast reconstruction in-depth, thereby increasing the meaning and understanding of this phenomenon. This approach was also indicated by a lack of other qualitative studies in this field of research (Harcourt & Rumsey, 2001).

Once a qualitative design has been decided upon, the researcher must then choose from an evolving range of methodologies. For example, the suitability of discourse analysis was considered at an early stage of this project. Dallos & Vetere (2005) describe that discourse analysis is based on the premise that our experiences are created through the interactions we have with one another and so it is suitable for data collected from a social constructionist perspective. However it also concerns the analysis of sub-textual information, which is not an intended goal of this project. Instead, it appeared that Interpretative Thematic methods were more likely to be the most appropriate approach, due to their focus upon extracting major themes in participants' accounts which can then be connected and developed into small-scale theories (Dallos & Vetere, 2005).

The two main types of Interpretative Thematic methods of analysis are Grounded Theory (Glaser & Strauss, 1967) and Interpretative Phenomenological Analysis (IPA;

Smith, 1996). It was necessary to examine both methods closely so that the most appropriate approach could be assumed. While both methods take the constructivist view that 'there are external realities but we can only ever know them through our own subjective lenses' (Dallos & Vetere, 2005; p.52), Grounded Theory and IPA differ in a number of important regards. The most perceptible difference between these two methods surrounds the matter of theory generation. The primary goal of Grounded Theory is the development of a middle-range theory, an explanatory framework which adds to our understanding of the phenomenon under study (Willig, 2001). In contrast, IPA is less interested in modelling themes and issues and seeks instead to explore and test current theories.

A number of other factors contributed to the rationale for using Grounded Theory over IPA. Grounded Theory advocates maintaining a distance from the relevant literature in order to avoid 'contamination' of the study (Charmaz, 2006). IPA on the other hand aims from the beginning to link data with the existing literature, therefore the researcher is required to take an interpretative stance from the outset. Inherent to Grounded Theory, the researcher only moves to an interpretative level of analysis following initial exploratory analysis, allowing initial categories to be identified and developed free from prior theoretical influences (Strauss & Corbin, 1990). Furthermore, it should also be noted that of the two methodologies, Grounded Theory is the more widely established, with more rigorous procedures and quality standards (Strauss & Corbin, 1998). Overall, taking these factors into account, Grounded Theory was decided upon as the most suitable methodology for this project.

2.1.2 *Grounded Theory*

Following 40 years of development and practice, Grounded Theory is now the most widely used and popular qualitative research method (Charmaz, 2006). The approach has been applied to a wide range of disciplines and subject areas, from the study of terminally ill patients' awareness of dying (Glaser & Strauss, 1965) to the recruitment processes of headhunting companies (Konecki, 1997). However, the Grounded Theory approach can be seen as being particularly well suited to psychotherapy-based research due to its ability to let participants' accounts speak for themselves (Dallos & Vetere, 2005).

Coolican (2004) describes that Grounded Theory was introduced in an attempt to counter the effect of the dominant hypothesis-testing models. As an inductive method of data collection and analysis, the Grounded Theory approach does not attempt to test theories but rather to develop or build understanding (Dallos & Vetere, 2005). By following systematic data collection and analysis procedures, a middle-range theory can be devised directly from empirical data, i.e. the theory is 'grounded' in the data (Glaser & Strauss, 1967). An initial substantive theory may be developed into more abstract formal theory following further exploration in different settings.

Theoretical sampling is one of the key procedures that underpins the Grounded Theory approach (Charmaz, 2006). It can be described as the task of seeking new data when the emerging theory directs that a new area be explored further, e.g. purposively selecting new participants on the basis that their story may help to develop the growing concept. The grounded theory is then refined by searching for

differences and similarities between subsequent interviews. In order to do this, all interview data must be 'coded' and analysed during the data collection stage.

The coding process, which Charmaz (2006) describes as generating the bones of one's analysis, involves fragmenting the data into individual phrases, lines, sentences etc, and then naming each segment of the data with a category label. Categories can function as descriptive labels, but as analysis progresses, categories and coding become more analytic and interpretative (Willig, 2001). Ideally, category names should be 'in-vivo', meaning that they mirror the words or phrases used by participants (Charmaz, 2006). This helps the researcher to minimise the influence of existing theory.

Following coding, the process of 'constant comparison' begins. This involves comparing each piece of data with the other and with emerging categories and theories, leading to the potential identification of sub-categories. Willig describes that constant comparison "ensures that the researcher does not merely build up categories but also breaks them down again into smaller units of meaning" (2001; p.34). The data collection phase of the project ceases when no new information or categories are found, also known as 'theoretical saturation' (Glaser & Strauss, 1967).

Throughout coding and analysis in Grounded Theory, the researcher continually makes 'memos'; records of their ideas and emotional reactions to the data and emerging categories (Dallios & Vetere, 2005). Tentative conceptual or theoretical linkages can also be noted in this fashion. The process of memoing facilitates theoretical sampling and hence the development of theory or the 'core concept'

(Glaser and Strauss, 1967). Reflexive practice such as this allows the researcher to keep a detailed record of the theory generation process.

Following analysis, categories are sorted and integrated together to provide an explanatory framework for the phenomenon under study (Charmaz, 2006). The resulting theory is often presented in the form of a diagram so as to provide a visual representation of the relationships between categories. Strauss and Corbin (1990) suggest that the quality of a Grounded Theory study can be ascertained by considering, for example, the coherence of categories/theory and the significance of theoretical findings.

In summary, Grounded Theory presents a systematic but flexible methodology suited to this project. It was chosen due to the desire to develop new theory in a manner which would most accurately reflect the participants' experiences. However, before commencing with the study, it was important to note the schism in method which has influenced Grounded Theory since the early 1990's. Where Glaser and Strauss were once united in their methodology, Willig (2001) reports that they went on to disagree regarding a number of important practical elements, with Glaser (1992) arguing that Strauss & Corbin's (1990) version of Grounded Theory was too prescriptive and therefore would interfere with the process of discovery. However, the present researcher felt a clearer identification with Strauss and Corbin's approach, which acknowledges the need to incorporate some deductive analysis, due to it being unavoidable that our earlier knowledge of relevant theory will impact upon the data's interpretation (Kelle, 2007).

2.2 About the Participants

2.2.1 *Breast Reconstruction Participants*

The inclusion criteria for this project were designed to maximise the available sample, which was known to be limited. Participants were required to be aged 18 years or older at time of diagnosis; to have had a diagnosis of breast cancer; to have undergone breast reconstruction surgery following full or partial mastectomy; and to be able to engage with support services, e.g. patient-led breast cancer groups.

Breast reconstruction participant exclusion criteria were treatment with chemotherapy or radiotherapy within the past three months; and a diagnosis of terminal cancer. Those who had undergone reconstructive surgery in recent months were not excluded from participating, nor were those with metastatic cancers, i.e. breast cancer having spread to other part of the body. The decision to include these potential participants at the recruitment stage was made in collaboration with members of the local Breast Care Team who felt that these women's attendance at a support group would be evidence of their ability to participate.

2.2.2 *Sampling*

The research aims for this project required that the experiences of a specific group of people be studied, i.e. women who had undergone breast reconstruction surgery following treatment for breast cancer. As such purposive sampling techniques were employed (Kelle, 2007). In addition, as data collection progressed, further

theoretical sampling took place according to the descriptive needs of the emerging concepts.

A small number of participants were identified via snowball sampling. This form of sampling is described as being appropriate if the population under investigation is small or difficult to access (Coolican, 2004) and involves asking the existing participants if they know someone else who may wish to take part. If deemed to meet the research inclusion criteria, this person is then invited to contact the researcher for more information.

Planned sample size was based upon Dallos and Vetere's (2005) recommendations that participant numbers must be large enough to allow the identification of sufficient categories, but not so large as to exceed the limits of what we can usefully make sense of. It was hoped that a minimum of six interviews would be carried out, with further respondents being interviewed as part of the theoretical sampling process until saturation was reached.

2.2.3 Recruitment

Recruitment in this study was facilitated by members of the local Breast Care Team. Participants were identified through their attendance at local breast cancer support groups. Members of the Breast Care Team agreed to introduce the planned project to potential participants and enquire as to whether they would like to invite the researcher to attend a future group meeting to describe the project further, with a view to recruiting group members as participants.

Permission granted, the researcher attended a local support group to describe the project. Although it had been planned that three separate groups would be visited, the project presentation was subsequently only provided at only one group. This was due to one group being cancelled as the facilitator was unavailable, together with there only being one potential participant within the other support group. At the group which did receive a presentation, those interested in participating were provided with a Participant Information Sheet (PIS; Appendix A), including the researcher's contact details so that potential participants were able to ask any questions. A reply form with a stamped addressed envelope was attached for participants to return, indicating whether or not they wished to participate. Once patients had returned completed reply forms they were given a one week minimum cooling off period, during which they could consider their participation in the current study. The researcher then telephoned those who wished to proceed to answer any remaining queries and to arrange one-to-one interviews at the participants' convenience and preferred location.

To access further potential participants, the Breast Care Nurses agreed to post the PIS directly to others who met the research criteria. Participants were then only contacted by the researcher once they had returned the reply form. At no time did the researcher have access to patient details. Additionally, as mentioned earlier, one participant was identified via snowball sampling. The existing participant was given an extra copy of the PIS to give to her friend, though she was not contacted by the researcher until she had returned a reply slip independently.

2.3 Ethical Issues

A project proposal was submitted and passed by the Fife and Forth Valley Research Ethics Committee and by the University of Edinburgh DClinPsychol Programme Team (see Appendix B). Each ethical issue was considered and addressed to ensure that the study was carried out to the highest ethical standards expected by the British Psychological Society's Code of Ethics and Conduct (BPS, 2006).

Ethical standards were also ensured by adhering to the *prima facie* principles of autonomy, beneficence, non-maleficence and justice. Regarding autonomy for example, it was vital that informed consent was gathered for all participants. All potential participants had the study explained to them in person or on the telephone and were provided with a written information sheet, detailing the nature and purpose of the study. Potential participants were then invited to return a reply slip, indicating their willingness to take part. At the time of interview, participants were asked to sign a written consent form (Appendix C) indicating that they were happy to proceed and aware that their input was on a voluntary basis. The consent form also ensured that the participants were aware that their interview would be recorded and informed them how the data would be stored, i.e. all information pertaining to the research was stored in locked cabinets or on password-protected computers.

It was also important that the principles of beneficence and non-maleficence were adhered to throughout the period of research, i.e. ensuring that the project would help others and do no harm. It was acknowledged that the interview process may be distressing for some participants, or possibly that some participants may be identified

to have clinical levels of anxiety or depression. As stipulated by the NHS Fife Research Ethics Committee, a standard letter was sent to all participants' GPs (see Appendix D), providing basic information about the study and offering follow-up support with Clinical Psychology services if required by participants. In this instance, it was agreed that a formal referral to the Clinical Psychology Health Specialty would be appropriate. Alternatively, the researcher was available to offer informal advice and support either directly or by telephone contact at any time during the study. The consent forms also advised participants about the use of direct quotations in the project write-up, noting that a quotation would not be used if it could potentially lead to the participant being identified.

Lastly, it was felt that participants may indeed benefit from having the opportunity to discuss how their breast cancer and reconstructive surgery experiences may have affected the way they view themselves, as such issues are often overlooked during treatment and recovery stages.

2.4 Research Context

Dallos and Vetere (2005) suggest that it is important to consider the social context within which research is conducted, so that we can be aware of outside influences and potential bias. The research context for this project includes the support groups from which participants were recruited, together with the researcher's own background and clinical experience.

2.4.1 Support Groups

The three breast cancer support groups from which participants were recruited are similar in their organisation and goals. Covering different geographical areas of Fife, Support Groups 1 and 2 are open to women of all ages, at any stage of the breast cancer journey. Support Group 3 is exclusively available to pre-menopausal women and aims to focus on the needs of younger women through mutual support. All three groups meet on a monthly basis, with breast care nurses in attendance to offer support and advice. The meetings are run on a very informal basis and support continues outside the meetings via the telephone or face-to-face contact. The groups also regularly hold alternative therapy sessions and are involved in fund-raising activities. It was felt that this was an ideal context from which to recruit participants as their attendance indicates an openness to discussing potentially distressing issues and a familiarity with telling their own and hearing others' stories.

2.4.2 About the Researcher

It has been reported that Bertrand Russell suggested "an open mind is also likely to be a vacant one, for we cannot altogether avoid preconceptions if we want to make progress in a field" (Dey, 2007; p.176). The nature of qualitative study means that, in addition to the research participants, the researcher too becomes an active participant in the process. It is therefore important to consider the potential influence of the researcher's clinical knowledge and personal background upon the interpretation of findings. Regarding the current study, the researcher does not have any personal experience of breast cancer, mastectomy or reconstruction surgery, which could have lead to the presence of preformed ideas about likely findings.

However, having clinical experience of working with women who have been treated for breast cancer, the researcher has witnessed the difficulties associated with accommodating these experiences into their lives. This study grew out of a desire to understand and represent that experience to a fuller degree.

2.5 Procedure

2.5.1 *Data Collection*

Recruitment proceeded as outlined in Section 2.2.3. Once recruited, no participants withdrew from the study. Participants were contacted one by one to arrange a suitable time and place to meet. The interviews, carried out over an 8 week period, took place individually at the participants' home or in Clinical Psychology clinic rooms in hospital settings. It was decided that loosely semi-structured interviews would be the best method of data collection. While providing a structure to guide the process, this interview approach allows an open and flexible exploration of the issues under study and so still permits the inductive data collection appropriate to a Grounded Theory methodology (Dallos & Vetere, 2005; Willig, 2001).

An interview schedule with non-directive, open-ended questions was prepared, based around the research aims (see Appendix E). The schedule was not piloted with the first participant as the researcher did not wish to lose this valuable data when only a small sample was available. Further, the Grounded Theory approach allowed for changes to be made to the interview schedule in order to further explore emerging themes. As an alternative to piloting, the interview questions were discussed with

members of Breast Care Team to assess their suitability. Each interview began with the question 'Can we begin by hearing a bit about when you were first diagnosed, and when you first heard about breast reconstruction surgery?'. The order of the subsequent questions was flexible and typical examples included 'How do you feel breast reconstruction has changed the way you see yourself?' and 'How have other people reacted to your breast reconstruction?'. Not following the interview schedule in a rigid way allowed a process of reflecting and probing to be adopted, with prompts such as 'Can you tell me more about what you said earlier when you were talking about...?'. It has been recognised that adopting a more 'conversational' style of interview can help to build rapport with the participant and encourage disclosure (Dallos & Vetere, 2005). Constant comparison led to further questions being developed and other questions dropped as interviewing and analysis proceeded side by side.

At the end of each interview, participants were thanked for their time and effort and the researcher's contact details were highlighted once again to ensure that the participant was fully aware that she could get in touch if distressed by the interview process. Participants were also asked if they would be willing to provide validity feedback on the findings, via a brief telephone interview, following analysis. All agreed to this request.

2.5.2 Data Management

The digital recordings of interviews were transferred to computerised voice files and transcribed verbatim using Olympus transcription software. Interviews ranged in

length from 35 minutes to 1 hour and 5 minutes. At this point all transcripts were anonymised and all digital recording files were deleted. Interview transcripts were analysed via the NVivo 8 package (QSR International, 2008). The use of such computer packages is recommended for qualitative projects, however Willig (2001) warns that the researcher must be careful not to attribute the programme with any creative abilities and should instead view it as a research tool only.

2.5.3 Data Analysis

As indicated by authoritative texts on Grounded Theory procedures (e.g. Charmaz, 2006; Strauss and Corbin, 1990), data were analysed using a two-step method. Memoing took place throughout all stages of analysis. As each transcript was completed, the material was read and re-read. The first stage of analysis, called explorative or line-by-line coding, allowed the researcher to become immersed in the participants' stories of the phenomenon under examination (see Appendix F for an example). By beginning with a detailed method of coding like this, the researcher avoided the risk that their attention might be captured by a striking event (Willig, 2001), or perhaps influenced by preconceived ideas. Line-by-line coding ensured that less obvious but equally significant categories were not overlooked, therefore making certain that the resulting theory was properly 'grounded'. In-vivo codes were used wherever appropriate.

Following initial coding, which fractured the data into distinct codes, axial coding was used to bring the data back together again into a coherent whole. This involved specifying the properties and dimensions of the main categories by sorting and

synthesizing the data product of open coding. At this stage, coding became less descriptive and more interpretative. Analysis was centred on theorising about the relationships between categories. The constant comparison of data and codes led to previously identified categories being grouped when conceptually similar, then merged and renamed if appropriate (see Appendix G for samples of category layout in NVivo 8).

As the interviews progressed, thematic categories identified from participant data were introduced into subsequent interviews to enable theoretical sampling. Approximately two-thirds of the way through data collection, the core category was identified. Selective coding was then utilised, whereby concepts which could not be related to the core category or its subsidiaries were no longer explored. Further comparison of categories and sub-categories continued so that the connections between them could be made more explicit (see Appendix G for NVivo 8 nodes). Following the completion and analysis of ten interviews, it was felt that theoretical saturation had been achieved for the purpose of this study. The categories and memos were then sorted into a structure which seemed to represent and clarify the theoretical relationship between breast reconstruction and self-image. At this time there was a return to the relevant literature, exploring for material which could help to further develop and validate the emerging theory.

2.5.4 Ensuring Quality

The process of triangulation has been suggested as useful in ensuring the validity of a Grounded Theory project (Dallo and Vetere, 2005). Triangulation is achieved by

gaining different perspectives on the same phenomenon. This enables the researcher to strengthen her understanding of, and confidence in, the research findings. The differences and similarities found in the other source are then integrated into the emergent theory.

Dallos and Vetere (2005) suggest that a focus group can be used as a method of triangulation and so, following the completion of the breast reconstruction participant interviews, a meeting was arranged with three members of the Breast Care Team. It was felt that the team's perspective would be highly valuable considering the experience gained by working on a daily basis with women who have undergone breast reconstruction. Focus group participants were provided with Staff Participant Information sheets and asked to sign consent forms (see Appendix H for both) prior to taking part in the discussion.

The interview was loosely structured on the topic of breast reconstruction and women's self-image, covering similar issues to those that had arisen during the reconstruction participant interviews. Unfortunately, due to demands upon the participants' time, the focus group was briefer than had been planned. The discussion was audio-taped but not transcribed verbatim, however the researcher made notes throughout the discussion which were then used to pinpoint shorter exchanges for transcription.

Dallos and Vetere (2005) also describe the process of respondent validation, commonly used in Grounded Theory, whereby participants' views on the

interpretation of the data are sought. The emergent categories were discussed with a sample of three breast reconstruction participants during brief telephone interviews. They were invited to state if the findings seemed 'true' to them, for example. It was felt that seeking 'testimonial validity' like this helped to contribute to the credibility of the study (Barker & Pistrang, 2005). Additionally, the researcher's clinical supervisor cross-checked a number of transcribed interviews annotated with initial codes and memos in order to validate the emergent categories.

Quality can also be demonstrated by producing an audit trail (Dallos and Vetere, 2005; Strauss & Corbin, 1990) which illustrates how the researcher moves from raw data to theory generation. A useful audit trail typically comprises of memos and examples of various stages of coding and analysis, so that readers can assess the project's progress and the coherence of the findings (see Appendices F & G). A research diary was also kept to record the researcher's personal reflections on the process (see Appendix J). Dallos and Vetere (2005) describe that reflective journals are usually kept throughout the research process so that thoughts, emotional reactions and links to theory can be recorded at all stages of the project. By noting personal motivations and biases, the research diary can aid the researcher in keeping a clear distinction between his or her beliefs or opinions and that of the participants. This ensures that the findings are securely rooted in the data.

2.5.5 Generation of Categories

The categories identified in this study were developed gradually over the period of data collection and analysis. As each interview was conducted, the narrative

transcripts were examined and initial themes were noted. These themes were then incorporated into subsequent interviews to ascertain if they were important to other participants also, as per Grounded Theory methodology. Themes evolved into fuller categories if highlighted as relevant and discussed in detail by participants. The dominant elements of each category could be identified during the initial stage of data collection, with some fluctuation of more minor themes between the following individual interviews.

The core category is composed of principal categories and their underpinning subordinate themes. The main categories and their secondary themes represent additional findings which are distinct from, but complement, the core category. While reflecting important aspects of breast reconstruction’s role, they do not directly underpin the core concepts highlighted by this project. A diagrammatic representation of the category hierarchy is shown in Figure 1.

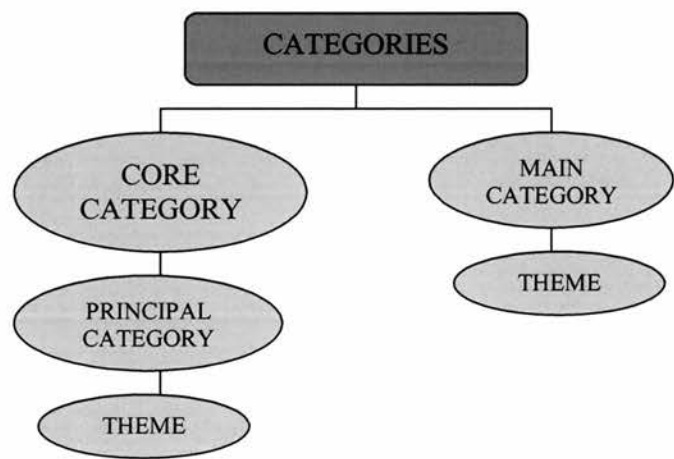


Figure 1 Hierarchy of Categories

FINDINGS

In this section, the categories generated will be identified and discussed, supported by direct participant quotations. The findings of the focus group will then be described. Lastly, the emergent theory of breast cancer, breast reconstruction and self-image will be outlined.

3.1 Participants

Ten female participants were approached and recruited in total, with at least one being drawn from each of the three support groups. No potential participants refused to take part or withdrew from the study. Participants ranged in age from 31 to 60, with six having undergone immediate reconstruction and four having delayed reconstruction. The length of time since surgery ranged from seven months to nine years. Two of the participants had experienced a recurrence of their cancer but did not have a terminal cancer diagnosis, hence they were eligible for inclusion in the study. Further participant data, including marital status and the type of reconstruction undergone (e.g. implant vs. autologous), is presented in Table 1.

3.2 Overview of Data Categories

Analysis of the interview transcripts generated one core category, comprising two principal categories, with a further two main categories, as shown in Figure 2. The core category was entitled "*Feeling like me again*" and illustrated the participants' experience of how breast reconstruction can aid the restoration of normality in their

	Age	Relationship status	Timing of reconstruction	Type of reconstruction	Time since reconstruction (years)	Employment status (at surgery)	Prior experience of BC	Current health status
Pt 1	35	Married	Immediate	LD Flap	4	Employed	No	Clear
Pt 2	60	Married	Delayed	Implant	9	Employed	Yes	Clear
Pt 3	36	Divorced	Delayed	TRAM Flap	3	No	Yes	Clear
Pt 4	50	Married	Immediate	LD Flap	8	Employed	No	Clear
Pt 5	31	Married	Immediate	LD Flap	7 months	No	No	Clear
Pt 6	45	Single	Delayed	Implant	2	Employed	No	Clear
Pt 7	44	Married	Immediate	Unknown	8	Employed	No	Clear
Pt 8	40	Partner	Immediate	Implant	4	Employed	Yes	Clear
Pt 9	54	Married	Delayed	LD Flap	8	Employed	No	Metastatic
Pt 10	43	Married	Immediate	LD Flap	3	Employed	No	Metastatic

All participants white females.

Table 1 Additional Participant Data

lives and in how they see themselves. The two main categories were entitled “Moving on” and “Image of sick person”.

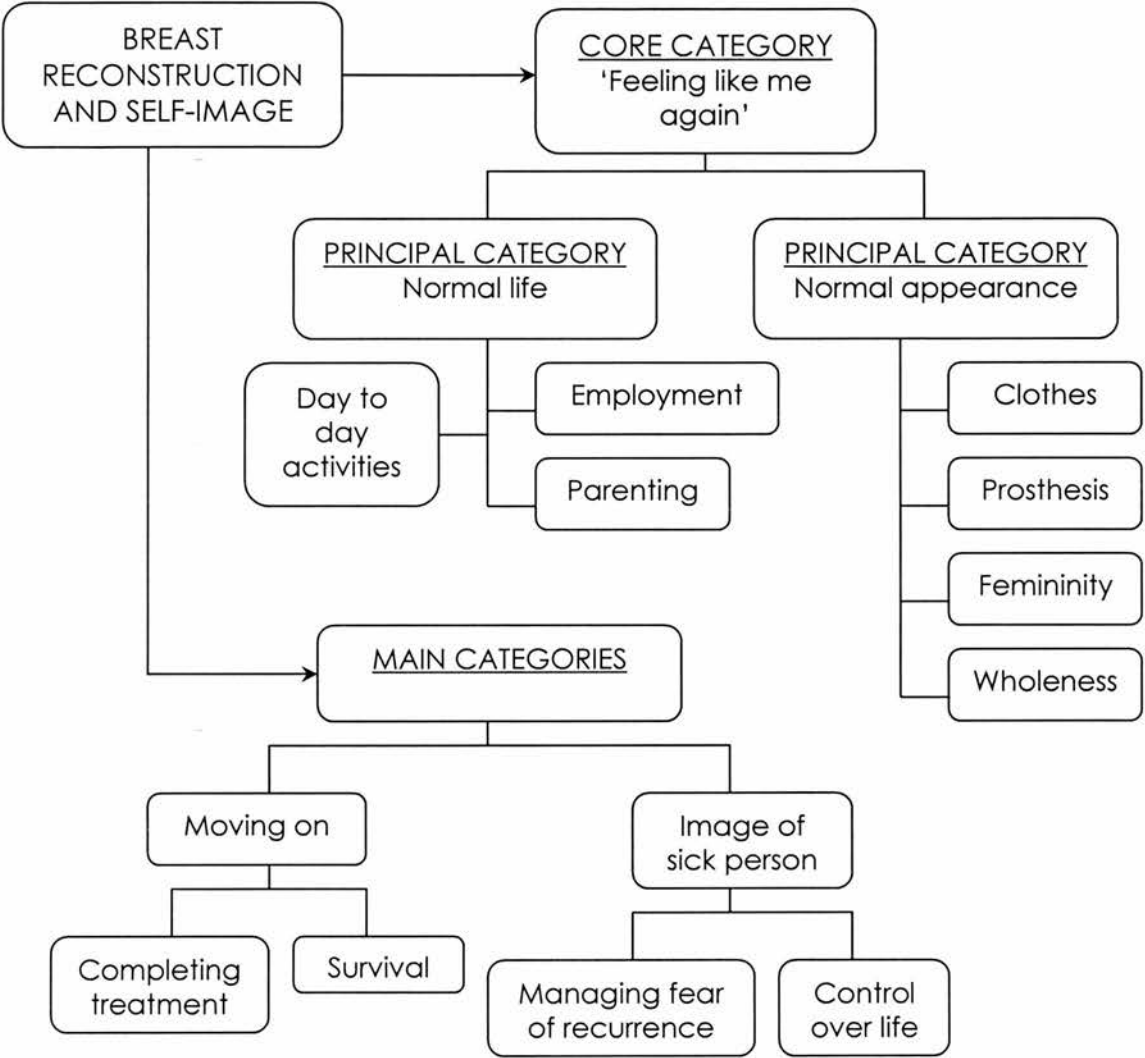


Figure 2 Categories related to Breast Reconstruction and Self-image

3.1 Description of Core and Principal Categories

3.1.1 Core Category – ‘Feeling Like Me Again’

The core concept and its subcategories will be discussed in some detail and the participants’ words will be used to illustrate themes. Entitled ‘*Feeling like me again*’, the core category emerged as a reflection of the participants’ beliefs that breast reconstruction surgery served to facilitate a sense of normality in their lives and in how they see themselves. This finding is summed up by the following quotations:

“I would definitely say the reconstruction has helped me... be more like myself.” (Pt 1)

“For me, I would have said it’s very much part of the healing process... because it was something that I needed to do for myself, to make me feel normal, if that’s the right word to use... to be back to where I was prior to the surgery basically.” (Pt 7)

For immediate surgery participants, as above, it was clear that they expected their self-image to still be affected by the mastectomy, despite not experiencing what it would be like to live without a reconstructed breast. As we shall see, in these cases, breast reconstruction appears to allow self-image to be *maintained* throughout treatment. For delayed surgery participants, the disruption to their self-image was perhaps lengthier and so reconstruction in these cases can be seen to play a role in *restoring* day-to-day functioning and self-image. The following quotations were gathered from delayed surgery participants, who describe feeling unable to ‘be themselves’ until reconstruction surgery had taken place:

I got [the reconstruction]... to make me the person that I looked like before... to give me the same image that I had before.” (Pt 6)

“After the reconstruction, I was so pleased... you know that I felt so good, and that I was starting to recover and I was starting to get back to... being me.” (Pt 9)

A number of participants, particularly those who had undergone delayed surgery, described their belief that without breast reconstruction, they would feel different from other people. Some reported being plagued by feelings of disfigurement:

Reconstruction is [the] choice to be normal... You feel normal the same as everybody else. Once I got 2 boobs, I thought ‘What can they get at me for, I look the same as everybody else now... I’m not a misfit now, a humpback hunchback type of thing’. (Pt 2)

The reconstructive surgery therefore appeared to minimise the women’s feelings of being different and allowed them to ‘blend in’ instead:

“Once you’ve got your bra on, it looks just completely normal, just the same as everybody else, eh?” (Pt 7)

As will be explored in the principal categories, participants described that being ‘normal’ was a combination of looking the same as other people and feeling like the person they were prior to surgery. It was described that the treatment of breast cancer via mastectomy can lead to women feeling like they have lost not just their breast, but other integral parts of who they are:

"I used to look in the mirror and cry every single day..., you know, because well you've lost, you've lost part of you for a start... And not only have you lost your breast, but you've lost so much, like you've lost so many dreams, and you've lost so many hopes, and you've lost... you know, so many things..." (Pt 3)

3.3.2 Description of Principal Category – 'Normal Appearance'

Throughout the interviews, participants described their reasons for choosing to undergo reconstructive surgery. In the majority of cases, concern about their physical appearance was paramount. The extent of unhappiness about their appearance varied between individuals. While some reported a milder degree of upset, others were extremely distressed by the outcome of mastectomy and felt they would have been unable to cope without reconstruction:

"Once I healed a bit [after the mastectomy], I couldn't look at myself, I was absolutely disgusted, my body image was... Just disgust, absolute disgust in my whole body... I couldn't look, it was just... horrible, and I never did look, except for that once, I stood and looked in the mirror and I could feel my stomach churning." (Pt 2)

"I would have been devastated. If I'd never got that chance [of reconstruction]... I don't think I would be able to accept being like that for the rest of my life. That would have cracked me up." (Pt 6)

While delayed reconstruction participants could comment on their feelings from experience, the immediate reconstruction participants could only say how they imagined they would have felt about their appearance if they had been required to wait for surgery. They described an expectation that they would have felt self-conscious about their appearance:

"I think I would have lost a bit of confidence in my body and I don't think that I would have... Like I'm happy to go about at home without any clothes on, but if that had been the case I think I would have kept myself covered up. I would have definitely felt that there was something missing..." (Pt 5)

The interview data also suggested that achieving a continuity of physical appearance was important to those undergoing immediate surgery in order to aid adjustment:

*"I was quite adamant, and once I'd decided that was it, knowing... that I was gonna have **something** is the big thing isn't it?" (Pt 4)*

"...waking up from the [mastectomy] operation... that would have been a lot more traumatic, had I not had the reconstruction done. In hindsight, it was pretty massive, you know the difference I think, having the reconstruction, waking up from an operation like that, and still having a breast as such, and waking up and not having anything, I think that probably psychologically would have been pretty major for me." (Pt 1)

The principal category of 'Normal Appearance' comprised four main themes, 'Prosthesis', 'Clothing', 'Femininity' and 'Wholeness', which will now be described in turn.

Prosthesis

The importance of appearance in self-image was strongly linked with the participants' feelings about prostheses. Not all participants had experience of using a breast prosthesis, as those who had undergone immediate reconstruction surgery had no need. However, all participants were aware of the common use of prostheses and had considered how using one may have affected, or did affect their life. Common

issues surrounded the impracticality of the prosthesis and its effect upon the wearer's self-confidence:

"And I didn't want to keep wearing a prosthesis, there was no chance of that... Cos I was in the garden one day and the prosthesis fell out, that happened twice, and that was embarrassing. There was nobody there, but it fell out... I felt it was degrading wearing that thing." (Pt 6)

"It's these awful chicken fillet things that they put in bras, and... there was a very nice lady on the ward who was having her second mastectomy, and she was very nice and she showed me her bras and the little pockets in them, and I just... I felt that that wouldn't give me the same confidence as having something fixed." (Pt 10)

Participants described that having to wear a prosthesis could act as a barrier to restoring their self-image due to its artificial feel and appearance. In contrast, it was felt that a reconstructed breast, particularly when autologous in type, felt more natural and part of their own body:

"I just felt out of shape and so scared... And getting a prosthesis... well, that was just an eyesore, it wasnae the same at all, obviously it wasnae the same. You're always conscious of it." (Pt 6)

"But I think if you have the prosthesis, it looks the same to everybody else from the outside, but I suppose you've always got that worry that it's not secure, it's not really part of you, whereas the new breast feels like part of me..." (Pt 5)

Furthermore, both immediate and delayed reconstruction participants described that prostheses can serve as a reminder of their lost breast and different appearance, leading them to feel burdened and constrained in their daily functioning:

"I mean my friend said she went to work one day and she'd forgotten to put it in and she was so paranoid for the rest of the day cos she couldn't take her jacket off, em... It's a constant reminder I think if you have to put something in your bra every day, whereas if you don't then.., you're a bit more free, emotionally and physically..." (Pt 1)

"It's almost like the prosthesis..., it's almost like you carry the weight anyway, but like it's weight on your shoulders, do you know what I mean? And then once that's gone..." (Pt 3)

In summary, the participants described that having to wear prostheses did not help them to feel confident about their appearance, was a source of some anxiety and was a barrier to improving or restoring their self-image.

Clothing

The difficulties associated with wearing prostheses were closely linked to the participants' feelings about their self-image and clothing. Interviewees described being limited in their choice of clothing, due to feeling uncomfortable or fearing that others may have been able to see the mastectomy site and/or their prosthesis:

"I couldnae like wear maybe a top to here, cos if I bent forward, you would see it, plus the fact I was flat here... you know it's really quite flat, well you were flat cos you..., you had nothing there. And with the prosthesis, it would come away from you... I just felt imbalanced." (Pt 9)

"I hated the fact that I couldn't wear the bras that I wanted to wear, or wear the tops that I wanted to wear... It was just frustrating." (Pt 3)

The participants reflected that following their breast reconstruction surgery, they quickly felt more freedom concerning their choice of clothing. In some cases this

contributed to improved body image, but more significantly it allowed the women to wear the same clothes they would have chosen prior to their diagnosis and treatment, in-keeping with how they saw themselves:

"I could look in the mirror, I could wear.. I went out and bought a load of new..., bras and things like that, pretty ones, because I'd been stuck with these great big ones to hold the prosthesis in..."
(Pt 2)

"I mean I can wear as low tops as I did before, whereas if you've not had it done, you're quite restricted cos I think it can come up quite high and you can see it, you know." (Pt 1)

Participants who had undergone immediate reconstruction described that this option helped to smooth the transition in their appearance, so that they didn't have to think about or plan for a change in their wardrobe:

"I was still wearing the same clothes, I still just threw my jeans and t-shirt on and away we would go, there was never a big thing about 'Oh, I haven't got anything suitable to wear' or whatever."
(Pt 7)

In addition, delayed surgery participants reported that while awaiting their reconstruction, they often had to wear something that they did not identify with, thereby further disrupting their self-image:

"I've always worn low tops so when I had to go into the high ones after the mastectomy, it was a complete new wardrobe of horrible, granny type clothes... They just weren't me." (Pt 2)

"... but the bras that you got were awful... they were horrible. That made me feel more..., less of a lady actually than not having the breast, you know because they were quite ugly..." (Pt 9)

In summary, having freedom of choice regarding clothing was reported to aid the participants in feeling more comfortable about, and in control of, their appearance.

Femininity

A further theme in the principal category of 'Normal Appearance' concerns the participants' description of the role that breast reconstruction played in restoring their feelings of femininity and womanliness. The interviewees reported the belief that as a disease, breast cancer is particularly effective at challenging women's image of themselves as feminine:

"And I think with breast cancer... you're kind of undermined as a woman... This cancer probably more than any other, strips away at your femininity because you lose your hair, you can lose your breasts, you can lose your ability to have children as well, all these things..." (Pt 5)

The majority of the participants described that their breasts are inextricably entwined with their sense of femininity and so the loss of one or both breasts through mastectomy attacked this aspect of their self-image, both physically and emotionally:

"It's part of your image, feeling like a woman... it's how you feel, that's part of you. Without that part of your body you don't feel like a woman. And I needed to be that person again, to feel like that again." (Pt 6)

"I can remember going to my GP after the mastectomy... and I was on chemo, and I said to him 'I think I'm turning into a man', and I mean I was a psychological mess, an absolute mess..." (Pt 2)

The delayed surgery participants described that undergoing surgery helped them to regain that sense of femininity and to feel confident and attractive as a woman:

"I mean 6 months ago I never looked in the mirror and saw an attractive person, a pretty person, a sexy person... And now I do." (Pt 3)

For immediate reconstruction participants, the interview data suggested that reconstruction allowed the impact of mastectomy upon femininity to be minimised by maintaining the female appearance:

"Just to have it all done on the one day, and kinda to wake up and be, well, I felt that I was still very much..., looked like a female. So, yeah psychologically for me, that was a huge thing that when I went to the hospital I looked very much the same as I did when I came home." (Pt 7)

It was also noted that femininity is not just based on attractiveness to others, but the woman's own confidence in her appearance. It was felt that undergoing reconstructive surgery can help to address this if necessary:

"But for me, I suppose it's not just what a man sees, it's what you see, you want to look in the mirror and think 'God, I do look alright today'... you know and walk down the street and think 'Look at her, I look quite good!'" (Pt 3)

It should be noted that sexual functioning, another aspect of femininity commonly affected by mastectomy, was mentioned very rarely by participants (the likely

reasons for this will be discussed later). A small number of interviewees did however comment on difficulties which could potentially arise in this area and expressed a belief that breast reconstruction could help, particularly for women who are not in an intimate relationship at the time of mastectomy:

"If it bothers you and then you start not wanting to get undressed, or being naked in front of them, it could have huge repercussions sexually, so I did it for that as well, you know." (Pt 1)

"I was quite secure in my relationship and it would never have bothered, never ever have bothered him. But you know..., you've got like young girls that are... aren't married or aren't in relationships, or for those that separate or get divorced when they're older, for them it must be..." (Pt 9)

A number of participants described that, in addition to the loss of the breast, their sense of femininity was significantly challenged by losing their hair following chemotherapy treatment:

"I mean I would say that losing your hair is probably one of the hardest things, because it's the fact that you just don't know who it is looking back in the mirror... cos it's just not you and again your hair is so much part of your femininity." (Pt 3)

In summary then, the participants described that breast reconstruction was key to helping regain their sense of femininity, however other changes to appearance, e.g. hair loss, also impacted upon this aspect of self-image.

Wholeness

The remaining theme in the principal category of 'Normal Appearance' concerns the importance to self-image of feeling 'whole again' following reconstructive surgery:

"I felt more whole again.. I don't know, it's really hard to explain... You know, you feel more whole again. I think for so long you look down and feel terrible and then all of a sudden it's gone because of the fact that your boobs are back." (Pt 3)

For immediate surgery participants in particular, the reconstruction was seen to minimise the loss of the breast and to counteract feelings of being incomplete by allowing a continuity of the breast shape:

"... I was quite relieved to learn that I could have it all at once because when I came in from the operation I didn't feel straight away as though something was missing, there was still something there in place of what had been there, so that was kinda comforting. You feel whole I suppose because, as I say you don't really feel as though you've lost anything." (Pt 5)

Thus, a wholeness of appearance can be seen as important to the restoration of self-image following mastectomy.

3.3.3 Description of Principal Category - "Normal life"

The second principal category concerns the participants' reflections about the importance of resuming their normal daily functioning to self-image. The interview data suggested that the women felt breast reconstruction would allow them to regain not just their normal appearance, but their 'normal life':

"Once you're over the surgery and chemo and what have you, your life goes back to normal, I was back to work and started going on holiday again, I just felt like myself." (Pt 7)

"I wanted to get my life back... I thought it would probably enable me to have more of a normal life." (Pt 1)

The participants discussed a number of tasks and responsibilities which they felt constituted large elements of a normal life. This category comprised three main themes, 'day to day activities', 'employment' and 'parenting', which will now be described in turn.

Day to day activities

Being able to resume their prior routine and carry out regular activities was significant to participants in aiming to achieve their desired self-image. A number of activities were identified as being key to normal functioning, including household tasks, shopping and going on holiday. Delayed participants described having felt limited in their ability to undertake and enjoy these tasks prior to reconstruction. Immediate surgery participants reported the expectation that without reconstruction, their daily functioning would have been negatively impacted:

"It's the fact that when you go out and you buy... everywhere you went, everything was like low, you couldn't buy a pretty bra... you couldn't feel sexy, you can't..., you know if you're going to the beach, or swimming pool and stuff like that... Reconstruction was never not an option for me." (Pt 3)

"I definitely would have been more self-conscious about..., baring myself on holiday, on..., even just going shopping I think would be a horrendous experience." (Pt 1)

It was noted that for younger women particularly, being able to carry out day-to-day activities with minimal impediment was important:

"I think for a younger woman..., a younger woman it is more important because of the different things that you're involved with, you're more active, I would say." (Pt 4)

Breast reconstruction was reported to allow participants to feel confident about behaving, in a range of environments, in the same way that they would have done previously:

"I wouldn't have any qualms at all about going into a changing room where there's a lot of people and stripping off my t-shirt or top or whatever. That sort of thing never bothered me before [the mastectomy] and I would do it now, I wouldn't think twice about it." (Pt 7)

To summarise, breast reconstruction was reported to aid women in resuming their day-to-day activities by increasing their confidence in both private and public settings.

Employment

Another important aspect of the women's 'normal life' related to employment. Eight out of the ten participants were employed at the time of their breast cancer diagnosis and treatment. The following participant, who underwent immediate reconstruction, described her belief that her return to work would have been disrupted otherwise:

"I probably would have had to go back to work and then go off and I probably wouldn't have had the same confidence, no I don't think so anyway. I mean I don't know, I've never worn a prosthesis, but I just don't imagine that I would have the same confidence and I would have been worried about that." (Pt 10)

Participants who had undergone delayed reconstruction described the difficulties of wearing a prosthesis in the workplace and the pressure of keeping their 'secret':

"I think what really... bending down... at my work I'm up and down quite a bit, so they had to... cos when you bend down, the prosthesis pulled the bra away [from the skin], so anybody looking would see the scarring, eh? That was the worst, trying to hide it from everybody." (Pt 8)

Reconstruction was seen to contribute to the women's ability to resume the normal day-to-day activities of their job, together with recovering or maintaining their confidence and their 'work identity', particularly for those in professional employment. For many of the interviewees, it was important for them to be able to be discreet about their ill health and surgical treatment, so that perhaps others would view them as the same, competent, person that they had been before:

"I have to think, even the [workplace] I'm at just now, I think they would be shocked if they found out now, because I don't think they'll have ANY inkling whatsoever... They just take me for what I am... and I think that's what saw me through... because I was not this dreadfully ill person. I didn't have to face a barrage of being asked how I was..." (Pt 4)

"And I felt that, when I would be sitting at my desk, they might be looking, you know just to see if there were any signs... As {Breast Care Nurse} put it to me, she said 'You need to have the confidence to sit in front of [others] and feel ok about yourself'." (Pt 10)

In summary, the interview data suggested that breast reconstruction played an important role in enabling the women to be confident in the workplace and to regain their image of themselves as a competent employee. Furthermore, by not having to wear prostheses, participants could be discreet about their surgical treatment, if this was their preference.

Parenting

A further theme found in the interview data related to living a 'normal life' was that of 'parenting'. Eight out of the ten participants were parents, six of young children. The interviewees reported the perception that for a mother, especially of young children, the breast is intimately connected to the woman's ability to care for her child and therefore her image of herself as a parent:

"I think when you're young and you're, you know you've not long just been breastfeeding your baby, and you know you're all of a sudden going through all this, you're not gonnae have a breast, and it's pretty massive." (Pt 1)

Losing a breast, and the changes in appearance this leads to, was also seen to hamper women's ability to take part in various activities with their children. For example, a number of participants described feeling uncomfortable wearing revealing clothes, such as swimming costumes, prior to reconstruction:

"It's something that if you don't have young kids, you can actually avoid that kind of thing without it being too much of a problem, whereas when you've got young kids, you're really so much more active as well." (Pt 3)

Many participants were apprehensive about the impact upon their children of looking different to other mothers. There was a belief that immediate reconstruction, in maintaining the woman's 'normal' appearance, would perhaps help the children to adjust to their mother's illness:

"Being able to go swimming and the fact that I could still wear the same swimsuit that I'd had before I ever had cancer, you know it's just all normality for the children, so I looked normal and they didn't see me sticking out like a sore thumb. I think it's just that they want their Mum to look like she's always looked, and they don't want to see horrible things like [mastectomies]." (Pt 10)

I was thinking about whether to have a nipple or not, I'm thinking 'well, if he ever sees me as he gets a little bit older, he might think that's a bit strange', so that, I think that may have an impact on whether I decide to go for more surgery or not as well." (Pt 5)

"Children are amazing in how they accept things, but as I say they haven't actually seen the reconstruction, but they see me in my bra, so I think they just think it's normal. And again, I think that's better seeing me in a bra than seeing me with chicken fillet things." (Pt 10)

A delayed reconstruction participant described that her young child appeared to notice the significance of the breast reconstruction surgery, for both mother and child:

"It was quite funny when I came back from the hospital and I'd had them both done, and she came in the next morning and said 'You've got 2 boobies now Mummy! It made me cry, she was obviously so pleased that I had two again...' " (Pt 3)

It was also suggested that reconstruction could aid the participants in protecting their children from unwanted attention and gossip, as they could feel confident that people would only be aware of the mastectomy if told:

"I think part of that was to protect my daughter as well, cos she was very young, and there was no way I wanted people looking at her and going 'Oh isn't it sad, look her mum's got cancer'... So it was just trying to be normal." (Pt 3)

"I have spoken to others who have been much more minimal about the information that they give, in their community and so on because they're afraid, for example, of other kids talking about, 'Oh, your mum's got cancer' or whatever, you know? So they've only told who they absolutely have to." (Pt 10)

Some of the participants also reported that maintaining their image as a mother was perhaps more important than their other roles in the family:

"I'm not saying I disregarded my husband, but I think I was probably more concerned about my relationship with my children... Just because of my appearance and what was going on. I was aware of the fact that I still needed to be the Mum that I had been and anything that went on, if I had bad days..., I was still Mum to my children." (Pt 7)

In summary, the participants reported that breast reconstruction can be important to a woman's image of herself as a mother as it enables her to take part in family activities and to 'protect' the children from certain difficulties associated with mastectomy.

3.4 Main Categories

In addition to the core concept and its principal subcategories, the present study generated two further main categories, these were titled "*Moving on*" and "*Image of sick person*". Both of the main categories, and their link to the core category, will be described.

3.4.1 Description of Main Category – “Moving on”

This category arose out of the participants’ frequent reports that undergoing breast reconstruction had helped them to ‘move on’ in their lives and in being able to regain their self-image. Interviewees described that throughout diagnosis and early treatment, the focus is very much on the present and coping with current events:

“I think that to begin with it’s very hard to even look to the future, to think of the future, to even plan anything for the future.” (Pt 3)

‘Moving on’ as a premise underpins the core category as participants described feeling less able to *feel like themselves again*, to restore their ‘normal appearance’ and ‘normal life’ until the impact of their mastectomy was put behind them. Reconstruction appeared to contribute to the women’s ability to move forward, both in practical (i.e. not having to wear a prosthesis any longer) and figurative terms:

“I think I wanted to... think, right that’s 2 years now, the cancer’s gone, it’s time to move...to move on. And em.. it did...” (Pt 9)

“I was so young and part of it is.., part of having the reconstruction done is being able to just put that behind you to get on with your life.” (Pt 3)

“Having the reconstruction probably helps you, not close the door completely, but kinda get it a little bit more closed than if you hadn’t...” (Pt 1)

This category comprised two subsidiary themes, ‘Completing treatment’ and ‘Survival’.

Completing treatment

For many participants, breast reconstruction was seen as the final phase of breast cancer treatment and so a natural point at which to begin looking forward and planning for the future.

"Once I came home from the hospital, I'd had all my treatments done, I was finished and I had a very positive attitude of 'Right, that's me done, I'm fixed, I'm sorted, I can only go forward now'." (Pt 7)

While not perceived as life-saving treatment in the same way as mastectomy, reconstruction was still depicted as being as integral to overcoming the negative effects of breast cancer. Participants described the completion of reconstructive surgery as a time for celebration and the conclusion of the long process of putting one's life back together, piece by piece, following a shattering diagnosis:

"And that was good to get the nipple, and then when you get the 2 afterwards, it's like 'Oh my God!' you know, so so chuffed! So I show them off to everyone! I'm always like 'Look, look!'... and they're like really really impressed, really really impressed... So it felt fantastic, it felt really great." (Pt 3)

"It's the final part to your jigsaw, that's what I think... the final part to your jigsaw, if you think of it in that way. If you didn't have that last part, there would be a piece missing. That's how I see it." (Pt 6)

It should be noted that some participants did not view reconstructive surgery as part of treatment, but rather they viewed it as an additional 'bonus' to their life-saving treatment, i.e. mastectomy. However this did not result in it being any less powerful to the restoration of women's self-image.

Survival

A further theme in the 'Moving on' category arose from the participants' description that, for some, breast reconstruction can be seen as a representation of survival. A number of participants reported the perception that their new breasts were symbolic of having beaten the cancer and thereby allowing their new lives to begin:

"This is going to sound silly, but my new breasts mean life... like my own breasts meant, well, not death, but pain and suffering, possible death... My reconstructed breasts are about life and living to me..." (Pt 3)

"I thought 'If the NHS is gonna spend all this money on me, they wouldn't do it if I was going to die', so I think that was the beginning of when I started to realise, life's gonna go on for me..." (Pt 2)

"As soon as I came home I just said to everybody 'Do you want to see it?'... Because I'm quite proud of it in a way, because obviously it shows that you've survived, you can tell the tale, you know?" (Pt 5)

Interviewees described that, in addition to this sense of survival, reconstruction surgery appeared to inspire them into doing things they would never have done before, due to increased confidence and a renewed impetus:

"The whole process I suppose is like a rebirth, like a new beginning, because you're getting a second chance, you know you're not gonna die, it's treatable, and it can help you to feel better in yourself." (Pt 5)

"I'll tell you how positive it is... For the fashion show I had this dress, it was long with no back and just the two straps coming up, and I went out with that on, which just confirmed it. I never ever would have done that before... Things that I would have never ever been able to do..." (Pt 8)

"And to see that folk that have had mastectomies and reconstruction can still do that..., it makes you stronger, it makes you do things that you wouldnae do before. It gives you strength and courage to do things. It gives you a whole new meaning, a whole new life doesn't it?" (Pt 6)

It was however acknowledged that a renewed vigour and 'lust for life' may be experienced by individuals who have survived any type of serious illness, not just those who have undergone mastectomy and breast reconstruction. Furthermore, a small number of participants did not support the suggestion that reconstruction may be symbolic of survival:

"I've never thought 'I have survived this' because of that. Other things have maybe triggered these thoughts, but not my reconstruction." (Pt 7)

3.4.2 Description of Main Category – "Image of sick person"

This category arose from the participants' reports that during breast cancer treatment and prior to reconstruction, their self-image was affected by the appearance of being ill or 'sick'. This served to add to the perception of being different to others, thereby creating a barrier to achieving a 'normal appearance' or 'normal life':

"I think it was you know, maybe someone looking at me and thinking 'Oh, there's something wrong with her' you know, and as I say, if they'd asked me I would have told them, but you know... if they thought 'Oh, she looks a bit funny' ..." (Pt 9)

"I don't want cancer to define or label me..." (Pt 3)

"You could have those thoughts [of being ill], and you did occasionally, but you could control them yourself.. And you didn't want other people having those thoughts or seeing you as a 'sick' person." (Pt 7)

The participants described that having had a mastectomy would be visible evidence of being sick and different to others, therefore breast reconstruction would again promote normality, allowing the preferred self-image to be achieved:

"I wouldn't have wanted somebody who knew me pointing out 'Do you know what happened to her? I wonder which [breast]...' , Now that could have been something really really silly... but I wouldn't want them... What they saw is what they got, do you know what I mean?" (Pt 4)

"You want to look normal..., like at the moment sitting here, it doesn't show that I've got cancer, but if I didn't have anything here (breast), then... that would change." (Pt 10)

This category comprised two further themes, 'Managing fear of recurrence' and 'Control over life'.

Managing fear of recurrence

"And to look in the mirror every day and to have that constant reminder..." (Pt 3)

Participants noted that, to a certain extent, undergoing breast reconstruction may have helped to temper their fear of the cancer recurring. While not taking this anxiety away entirely, it was reported that prior to breast reconstruction, the diseased

breast (in the case of immediate surgery participants) or the mastectomy scars (in the case of delayed participants) often acted as a reminder or prompt of having had breast cancer. This would then lead participants to become anxiously preoccupied with the possibility of their cancer returning:

"Yeah I think that... with the fact that you, you know you looked at yourself all the time, and it just reminded you of cancer, you know, what you had been through, ... and I just thought 'Well if I get a new breast, then maybe that'll take a wee bit of that away'." (Pt 6)

"I mean you're living... I mean you're living wi' it every day, you're dying every day... I mean that's how it feels at the time... there's never a day when you dinnae think about it... you wake up in the morning and it's staring you in the face... that was one of the reasons why I decided to get the, the reconstruction as well, cos it was staring me in the face and I thought 'well, it might help'." (Pt 9)

Following reconstruction it was felt that, although thoughts of recurrence were not completely gone, they were less frequent and participants perhaps felt more able to contain these cognitions and the accompanying emotions:

"It used to be the first thing on my mind in the morning and the last thing on my mind at night. It's not quite so bad now, but still, still there, you know, still a worry. Emotionally it's..., you can kinda, not forget about it, but you can forget about it more than if you hadn't had [reconstruction] done... You can get up in the morning and get dressed without thinking 'Where is it, where's my prosthesis?'" (Pt 1)

"Way back at the beginning every day I thought 'I've had breast cancer'... but now, I cannae remember the last time I got up and had my shower and thought that in the morning before getting dressed, so no... These issues, if I had these issues, have all gone." (Pt 7)

In summary, a number of participants noted that mastectomy scars prior to reconstruction can act as a negative reminder of cancer, whereas the reconstructed breast, although still a reminder, has more of a positive flavour and is consistent with a 'normal' self-image. However, it was acknowledged that the anxious preoccupation with recurrence may decrease naturally also, as a consequence of time passing:

"I think even though you have the reconstruction, it doesn't take away the fact that you had the cancer... Nothing will ever take that away, it just I think it's just because of the scars really... But they fade you know. And it just helps you to feel more whole again and more normal." (Pt 3)

Control over life

Participants reflected that undergoing breast reconstruction could be seen as an approach to taking control over their life back from the disease, allowing them to refute the 'image of a sick person':

"You know, again it was all about the control thing I suppose, you know, getting your life back on track again, and... trying not to be reminded, to just look normal." (Pt 9)

"Somebody wasn't coming to me and saying 'Actually we're going to take your breast away', I was saying 'Well you can take it away'." (Pt 3)

One participant described that undergoing breast reconstruction allowed them to avoid a potential barrage of questioning from acquaintances, as had happened when her daughter had gone through a period of illness:

“And I wanted to be in control too, because we’d had this time with {daughter} and folk would say ‘Oh is she still unwell..?’ and I thought ‘I can’t face this as well’... you know you’ve gone from that, so that probably coloured our opinion as well, and I didn’t want to be in the town centre and folk to come up, and for them to end up upset...” (Pt 4)

Participants noted however that exerting control over the ‘sick person’ image was complicated by hair loss, particularly when women find it uncomfortable to wear wigs and so wear head scarves instead:

“And I think also because it’s in everybody else’s face that there’s something wrong... ‘She’s not got any hair she must have.. whatever...’ and I think because, not that I get upset about what other people say, but I think I was in the mindset of thinking that ‘People will think she’s not gonna be here very long because if she’s lost her hair she’s obviously seriously ill...’.” (Pt 7)

In summary, participants described that undergoing reconstructive surgery assisted in restoring their normal self-image by counteracting the appearance and behaviours (e.g. fear of recurrence; loss of control) of a ‘sick person’.

3.5 Additional Findings

Participants described that their experience of breast reconstruction was overwhelmingly positive and typically exceeded their expectations, both in terms of appearance and the impact upon their goal of ‘feeling like me again’:

“I didn’t realise how big a difference..., I knew it was gonna make a difference, but not how big a difference it was gonna make to me.” (Pt 2)

"[The reconstruction has] been an integral part of it all, definitely. Helping you to... Just to get through it, to get through it all." (Pt 5)

However, the participants described that before breast reconstruction can take place, there are a number of potential barriers that women must overcome, namely 'Opposition from others' and 'Access to services'.

Opposition from others

The participants described that family members were often initially uncommitted to the idea of breast reconstruction, particularly delayed, due to the necessity for further major surgery. A small number of participants also reported having experienced very negative comments from acquaintances, suggesting that breast reconstruction is an improper use of NHS resources:

"It's almost like the attitude people have... "Well, you've got rid of your cancer and you're not dead so for God's sake be grateful, you're lucky you're here...". (Pt 3)

Participants described that that attitudinal barriers can be overcome if the woman is clear about her reasoning for undergoing the surgery. The majority reported that they had elected to undergo surgery because they felt it would have been difficult to 'feel like me again' otherwise:

"Everybody was saying 'Don't get it done, you've been through enough, don't get it done', but I wasn't doing it for anybody else, I was doing it for me, to make me feel better in here (head)... It was mainly psychological, it wasn't... I just felt better once it was done." (Pt 2)

"I got it for my own self, not for anybody else, just for me cos I wanted it, for my own peace of mind, that was why I got it done."
(Pt 6)

Access to services

A further barrier highlighted by participants concerned the variability of access to breast reconstruction services. It was described that if immediate reconstruction was not possible, perhaps due to radiotherapy being required, the wait for delayed surgery could be very lengthy and may add to women's distress:

"I waited 18 months for it and it was absolute hell, I mean it really was... and I honestly feel that if a dog bit your nose off, they wouldn't make you wait 18 months to get a new nose, and certainly if a man had his willy chopped off, they'd never make him wait 18 months before they put it back on. Maybe it's not quite the same, but it's not far off." (Pt 3)

Although participants agreed that mastectomy patients should take priority in surgery schedules, they expressed frustration that reconstruction was perhaps being seen as primarily a cosmetic procedure with minimal urgency attached:

"I kept waiting on the letter coming in and waiting on the letter coming in, and it wasnae, and it was never coming in... But I mean, not being selfish, I wanted it, but I totally understood that the cancer patients had to have his time first, ken what I mean? I couldnae go in just for the look of it when there was people needing a mastectomy quickly." (Pt 8)

In summary, the participants described that their goal of achieving a 'normal' self-image could be threatened by various barriers to accessing breast reconstruction, such as the attitude, from both the public and medical professionals alike, that the need for surgery is not urgent.

3.6 Focus Group Findings

The focus group discussion with members of the Breast Care Team was used to validate the breast reconstruction participant findings. The quotation source is not listed by job title so as to prevent the possible identification of participants.

3.6.1 *Core Category (including Principal Categories)*

The focus group participants provided support for the finding that reconstructive surgery plays a role in restoring not just physical appearance, but women's views of themselves also – helping them to 'feel like me again'. Participants described that this was particularly important when you consider the long-term effects of breast cancer, such as continued treatment with medication and regular follow-up appointments:

"You have to view breast cancer as a chronic disease, so they've got to look at it..., for a long time, so it helps to restore a degree of normality, and their normal activities."

The focus group participants felt that in order for women to feel that reconstruction will help them in achieving a 'normal appearance', it is vital to ensure that their expectations for surgery are accurate, i.e. being aware that breast reconstruction is not a 'cosmetic' procedure. It was felt that unrealistic expectations can hinder rather than aid adjustment of self-image:

"Sometimes the reconstruction might not live up to their expectations, they might be looking for a bit more. They think they're gonna get a breast, but you have to say, 'No, you're not gonna have a breast... the reconstruction is a mound that's attached to you that will look good when you've got clothes on'. They have to be aware of that."

It was felt that breast reconstruction would initially have the biggest impact in practical areas, such as not having to wear a prosthesis and having a wider choice of clothing. Interviewees suggested that this would then lead to restored confidence and self-esteem, particularly if their experience of using a prosthesis had been poor:

"If someone's lived with a prosthesis and really had a terrible time their whole wardrobe and what they wear, it can really help. If something happens with a prosthesis, it can really knock their confidence..."

The focus group participants also discussed the women's need to not be 'different' to others and agreed that breast reconstruction helps to achieve this:

"Say if someone's in a changing room and getting dressed in front of others and someone eyeballs them across the room – with reconstruction you look ok, you don't look bizarre or different."

Regarding women's ability to resume normal day-to-day activities, the focus group discussion confirmed that breast reconstruction can play a significant role in this area. The focus group also highlighted that reconstruction can aid women in their parenting responsibilities, by increasing their confidence to undertake energetic family activities, for example. It was further acknowledged that reconstruction surgery may allow women to 'protect' their children, if necessary, from having too much information about the illness and treatment:

"One woman didn't want her son to think that she was different, she couldn't face him saying 'My mummy's only got one boob', and that was a big issue to her, so she's now thinking along the lines of reconstruction... because of that."

Regarding employment, the focus group participants were unable to comment on whether breast reconstruction could play a role in aiding women in their return to the workplace as they had not encountered this suggestion before. The role of breast reconstruction in restoring women's sense of femininity and wholeness was not discussed due to time constraints.

3.6.2 Main Categories

The focus group participants were supportive of the finding that breast reconstruction can aid women in looking to the future and 'moving on'. It was felt that, particularly for women undergoing delayed surgery, breast reconstruction can encourage them to begin putting their cancer experience behind them and recapture their self-image:

"It can be like a real boost for them, both in terms of mood and also to spur them into action."

The focus group discussion on whether breast reconstruction can be seen as the final stage of treatment was focused on the definition of 'treatment'. It was felt that reconstruction cannot be seen as core treatment for breast cancer as it is not life-saving, however its role in treating the psychological after-effects of the disease were acknowledged. Focus group participants believed that reconstruction should be viewed as an additional treatment, not required by all:

"It's an optional extra... the majority of women will not choose to have a reconstruction. Obviously there are some constraints on some people, such as co-morbidity, but the majority don't, so I would imagine that they don't see it as part of the core treatment, it is that extra bit available."

The focus group participants described that some women who do not see reconstruction as optional are often subject to inaccurate preconceptions that it would be impossible to cope without it, perhaps having been influenced by friends, family, or the medical profession. The group were concerned that, prior to mastectomy, women often do not credit themselves with the ability to adjust, so instead they should be encouraged to challenge this view:

"People will come to the table with preconceived ideas... like 'If I need a mastectomy, I must have a reconstruction cos I would never ever deal with it if I didn't'. They usually arrive without a good concept of what it's about... thinking I don't think I can cope with having a mastectomy... but they do! It's part of a normal process..."

"There are a lot of ladies who think they'll have a reconstruction at the end of this, but then they change their minds because they cope with the mastectomy."

With regards to the theme of 'survival', the focus group participants described that in terms of symbolic meaning, they were aware that some women thought of their reconstruction almost as the 'spoils of war', the proof of the battle won against breast cancer:

"Some see their reconstruction as a badge of honour - they become very proud of it and are keen to show it off at a moment's notice."

However, it was stressed that women who have not undergone reconstruction often are proud of their mastectomy scars in the same way and so it was felt that this sense of survival is not limited only to women with breast reconstruction. Similarly, the focus group participants were reluctant to accept that reconstructive surgery may help women to address their fears of recurrence. It was felt instead that this is more likely to be due to a natural reduction of the anxious preoccupation over time:

"I don't believe it's the reconstruction that makes them think less about the cancer recurring, I think it's a time thing... If they find a lump or bump, it's still the first thing that comes back into their mind."

Further, the focus group members were unsure of the breast reconstruction's role in allowing women to counteract their 'image as a sick person'. It was felt that this would extend only to matters of appearance (by removing the need for a prosthesis) rather than how women see themselves:

"I'm not convinced of that... maybe in clothes, maybe externally to the world you can argue that, in terms of not having to wear a prosthesis."

3.6.3 Other issues

The focus group participants agreed that women often face opposition from others regarding their wish to have breast reconstruction surgery. This appears to be due mainly to the risks of undergoing further surgery:

“One lady wanted to have reconstruction, but her family talked her out of it, because she had to go back into hospital... But she came back 6 months later and said, ‘No, I’m doing it for me’ and then her family realised that she was truly doing it for herself and supported her.”

Overall, the group agreed that when choosing whether to undergo breast reconstruction or not, it is important that women have adequate time to consider their decision, as often there can be pressure to decide quickly, as with immediate reconstruction for example. The team felt that, if they choose reconstruction, women should be well-informed, aware of delayed surgery options, and able to make their choice independently:

“I think when they’re making their mind up, it’s difficult... others who are pro-reconstruction talk you into it, but equally they can be dead against it... It’s just getting that balance.”

“It’s important to have the option to come back later and get it done, once their treatment is completed, at a time when they’re ready and on their terms.”

The focus group participants concluded that patients’ individuality must be respected:

“It’s definitely not a fix all for everybody, it’s not right for everybody... nor is it wrong for everybody either...”

3.7 Model of Breast Cancer, Breast Reconstruction and Self-Image

Following analysis, the categories were integrated to create a model of breast reconstruction and self-image, as presented in Figure 3. The model conceptualises the relationship between women's self-image and the core and main categories. It is designed to illustrate the ways in which breast reconstruction surgery can aid women with breast cancer in re-establishing their self-image.

Three main stages of the breast cancer and reconstruction journey are described, namely 'Diagnosis and mastectomy', 'Reconstructive surgery' and 'Post reconstructive surgery'. The development of women's self-image is viewed across this context. The participants' comments regarding potential barriers to accessing breast reconstruction were incorporated into the model but do not interact with self-image. The model proposes that at the time of diagnosis and mastectomy, the image that a woman has of herself is challenged. While previously viewing herself as an active, healthy, 'whole' woman, she may now perceive herself to be confronted with the image of a sick person, incomplete and unfeminine. The loss of the breast affects not just her physical appearance, but her image of herself as woman and a mother, thus she is suddenly inactive and lacking control over her life - unable to 'feel like me'.

The model then advocates the view that through breast reconstruction, the woman can begin the process of adjusting to and reversing changes to her self-image. Reconstructive surgery first helps her to feel that she has a 'normal appearance' by

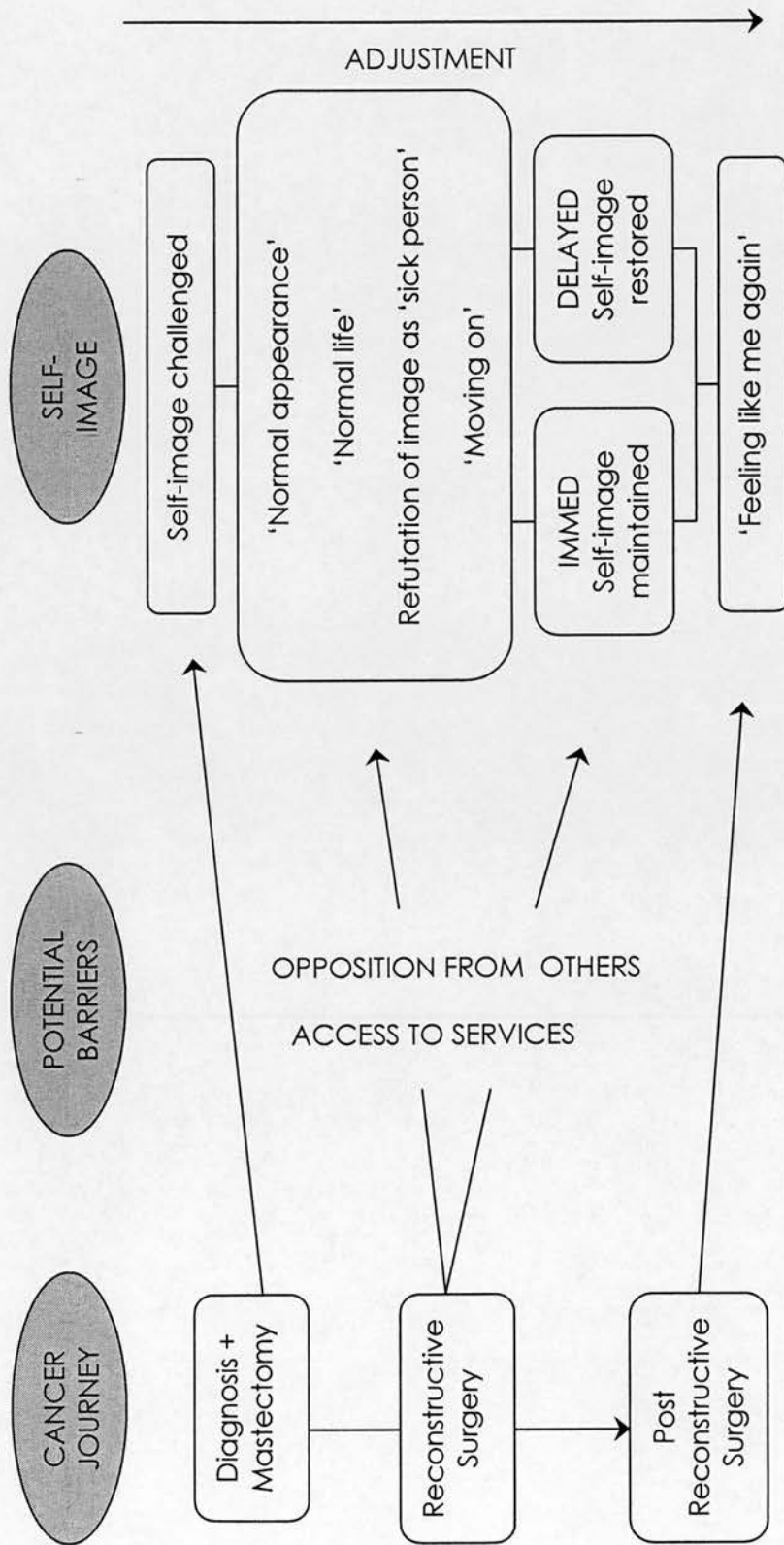


Figure 3 An integrated Model of Breast Cancer, Breast Reconstruction and Self-Image

promoting a wider choice of clothing and removing the need for a prosthesis. The reconstructed breast also helps the woman to regain her sense of femininity and wholeness. Concurrently, the woman can reclaim her 'normal life', particularly with regards to parenting and employment.

It is suggested that immediate reconstruction surgery allows the previous self-image to be 'maintained' on the whole by minimising the loss of the breast and providing continuity of appearance. Immediate reconstruction also offers minimal disruption to the woman's day-to-day activities, in the home as a mother and in the workplace. Where immediate reconstruction is not possible, delayed surgery allows the self-image to be 'restored' by resolving the physical loss of breast and providing a closer approximation of the woman's previous appearance. It then enables the woman to recommence her typical day-to-day activities. With both immediate and delayed reconstruction, the woman is able to gain control over her image as 'sick person' and close the door on her treatment. As she begins to plan for the future, she is able to once more 'feel like me again'.

DISCUSSION

This chapter will begin with an overview of the current research findings and is followed by a discussion of the main issues, with reference to appropriate literature. A critique of the project limitations will then be provided. The current study will conclude with the reflections of the participants and researcher, followed by implications for clinical practice and some final thoughts.

4.1 Overview of Research Findings

4.1.1 *Summary of Research Findings*

A number of themes were identified from the interview data and collated into categories. The core category was entitled '*Feeling like me again*' and conceptualised the participants' desire to restore themselves to the women they were prior to being diagnosed with breast cancer and having breast surgery.

The principal categories which comprised the core category were named '*Normal appearance*' and '*Normal life*' and were complemented by two further main categories, named '*Moving on*' and '*Image of sick person*'. Validation for these findings was sought via a focus group with members of the Breast Care Team. The categories were integrated into a *Model of Breast Cancer, Breast Reconstruction and Self-Image*, illustrating the role that breast reconstruction surgery can play in aiding the adjustment of women's self-image following surgical treatment for breast cancer, i.e. mastectomy.

4.1.2 Research Aims

It is also appropriate at this juncture to address the research aims which guided this study. The first aim sought to address the experience of breast reconstruction surgery and its effect on women's views of themselves (i.e. their self-image). The core and principal categories can be seen to answer this question by their description of breast reconstruction's role in allowing women to 'feel like me again'. With immediate reconstruction, it is suggested that self-image is preserved throughout the period of surgical treatment. With delayed reconstruction, it is proposed that the effect of surgery is to allow women to recover their self-image. It is not suggested that breast reconstruction changes women's image of themselves as such, but instead secures their pre-surgery self-image. Key aspects of self-image, such as a sense of femininity and wholeness, are also recaptured and strengthened in part through breast reconstruction surgery.

A further aim was to discover what role breast reconstruction plays in helping women to overcome the challenges of day-to-day life following a diagnosis of breast cancer. This study identifies breast reconstruction as playing a strong role in this regard. For example, reconstruction enables women to leave behind the inconvenience of wearing a prosthesis and to feel confident about carrying out typical daily activities, e.g. going to work and doing sport/exercise. Reconstruction also helps women to address the challenge of how to deal with the public presentation of their illness. For example, it allows them greater choice about how open they want to be with other people, so that they can keep their treatment via mastectomy entirely private if they wish. Further, breast reconstruction offers a

route to overcoming the challenges that breast cancer places upon participants' role as a parent, such as managing the anxiety children may feel about their mother looking 'different' or being 'sick'.

The next guiding aim of this study asked what role reconstruction has to play in aiding women's adjustment to their breast cancer and illness experience. The main categories of 'Moving on' and 'Image of sick person' can be seen to answer this question. It is suggested that breast reconstruction enables women to move on from their cancer experience by 'closing the door' on the treatment stage. It is also indicated that undergoing reconstruction can help women to better manage their image as a 'sick person' and can potentially reduce their anxious preoccupation with the fear of recurrence. The final aim of this study asked what additional meaning, if any, does breast reconstruction hold for women. It was identified that for some, reconstruction was symbolic of 'survival' and inspired women to attempt new and different activities. Further, reconstruction was found to enable women to gain a sense of control over the disease and so its meaning was not limited to issues of appearance and practicality only.

4.2 Discussion of the Present Findings

Hill & White (2008) describe that, in addition to the physical restoration of the breast, reconstructive surgery also has enormous psychological implications. Further, Potts (2000) states that breast cancer constitutes a "threat to the continuing reality of the self and the body" (p.104). Despite these assertions, there appears to be a paucity of

theoretical models relating to the role that breast reconstruction plays in women's self-image. The present study has demonstrated that the function of breast reconstruction surgery is not limited to improved satisfaction with appearance, but extends to enabling women to regain their preferred image of themselves across a range of settings. The Model of Breast Cancer, Breast Reconstruction and Self-Image presented in this paper offers a framework which can help to provide a greater understanding of women's adjustment following such surgery. The findings will now be discussed with reference to the existing literature. In addition, appropriate quotations from 'The Boudica Within' (Sassoon, 2007) are interspersed with this discussion. This book contains the photographs and stories of several women who have undergone breast reconstruction and was not read prior to analysis. The extracts presented are felt to provide support for the current study's findings.

4.2.1 Core and Principal Categories

'Feeling Like Me Again'

The emphasis upon achieving 'normality' found in the core and principal categories has been highlighted previously by a number of different authors and so offers support for their authenticity in this participant group. Emma, in 'The Boudica Within' (Sassoon, 2007) describes her decision-making regarding reconstruction:

"Not having reconstructive surgery was never an option for me... I felt I wanted to give myself every opportunity to carry on with life as normally as possible." (p.83).

In their qualitative study of the impact of breast reconstruction upon sexual functioning, Marshall and Kiemle (2005) found that "appearing normal" was linked

to self-image. Normality in this instance was defined as having equal breasts, in both the woman's and her partners' perception. Another qualitative study by Neill et al. (1998) explored factors that influenced women's decision-making about breast reconstruction. From interviews held at one and six months post-reconstruction with 11 women, they identified a main theme of 'Getting my life back' as motivation for undergoing reconstruction, i.e. returning the person's life back to what it was before diagnosis, or as close to this as possible. Neill et al. (1998) concluded that by helping them reach their 'normality goals', reconstruction "minimized the negative consequences of breast cancer and its treatment for the women in the study" (p.743).

Similar findings feature in the work of Truelson (2003), who carried out open-ended interviews with a sample of eight women. Truelson described that women are motivated to undergo reconstructive surgery due to "the desire to be 'normal' and to be perceived as having a 'normal' appearance to the outside world" (p.309). The participants in Truelson's study also related a wish to stay unchanged from their prior image of themselves. However, as this sample also included two women who had elected not to undergo reconstruction, there was evidence that some women are able to integrate the loss of the breast with their self-image independently. These findings cannot be authenticated by the present study due to the absence of 'non-reconstruction' participants.

Other support for the core and principal categories can be drawn from the work of Nissen, Swenson, and Kind (2002). Focus group participants, who had undergone immediate breast reconstruction, revealed that the surgery had helped them to feel

some form of 'normalcy' after their breast cancer treatment. This sense of normality was felt to apply particularly to the women's appearance. Frierson and Andersen (2006) report that perhaps the most apparent benefit of reconstruction is the positive impact on appearance. This includes simple, everyday matters such as not having to use a prosthesis and improved clothing choice and fit. This has also been described by Querci della Rovere (2004) and Reaby (1998). Numerous authors have identified improved body image as being a typical motivation to undergo breast reconstruction (Berger & Bostwick, 1994; Mock, 1993; Pusic et al., 1999). However, Crompvoets (2003) describes that to label breast reconstruction as having primarily cosmetic or aesthetic aims is controversial and provokes defensiveness among women.

Another aspect of 'normal appearance' identified in this study was a sense of wholeness. The data suggests that immediate reconstruction can minimise the loss of the breast by allowing a continuity of the breast shape. Other authors have described that, through reconstruction, women seek to restore their sense of wholeness (Berger & Bostwick, 1994; Hart, 1996). While a number of authors have similarly argued that immediate reconstruction helps women to find the loss of the breast less distressing (e.g. Al-Ghazal et al., 2000; Bostwick, 1995), others disagree. Hill and White (2008) suggest that although immediate reconstruction allows the form of a breast to be maintained, women do not perceive it to be the same as their natural breast and so reconstruction "becomes part of the loss as opposed to the solution" (p.85). These alternate findings may have resulted from immediate reconstruction patients having less time to acquire information and adjust to the idea of surgery, compared to delayed reconstruction patients.

Regaining femininity was identified by the present study as being key to a 'normal appearance' and feeling more like oneself. Marshall and Kiemle (2005) also found that some women felt that self-image was based upon their sense of femininity, associated with feeling good and looking good. In *The Boudica Within* (Sassoon, 2007), Katherine describes the impact of reconstruction in this area:

"For me my breasts and my femininity are one; when a woman loses them it's no different to a man losing his privates. [Now] my concerns about my femininity and desirability have vanished. Yes, you can recover both of these through reconstruction". (p.35)

Furthermore, Hamel (2007), discussing her personal experience of breast cancer, mastectomy and breast reconstruction, also describes a need for normalcy of appearance:

"...a return to normalcy - which is, in the end, all that us cancer women really want." (p.1)

However, a number of authors have questioned the accuracy of research findings that highlight the perceived need for normalcy. Manderson (1999) argues that breast reconstruction creates only an illusion of normalcy, while Cromptvoets (2006) agrees that it is not the breast reconstruction procedure per se that restores lost femininity and normalcy, but the elimination of the need to use a bothersome prosthesis. In recounting the breast reconstruction stories of five women, she suggests that "in contrast to the complete sense of self [women] expected to regain through reconstruction, they articulate a restoration that is simply pragmatic" (2006; 90). Cromptvoets (2006) describes that feminist analyses of this topic, though in the

minority, see breast reconstruction as a form of social oppression which feeds negative female stereotypes. For example, Ferguson (2000) suggests that against a background of the medicalisation of breasts, reconstructive surgery is being used to encourage women to conform to societal norms of the ideal female body. Despite this, Crompton (2006) concludes that for some women following mastectomy, breast reconstruction remains vital to self-image:

"... surgical breast reconstruction remains the only mechanism that will ultimately enable transcendence of the temporary mastectomised state and facilitate the reinhabiting of [the] 'true', familiar, embodied self." (p.91).

Further discussion on the social construction of women's self-image will take place later in this chapter.

The principal category of 'Normal life' identified the role of breast reconstruction in enabling women to recommence their typical day-to-day functioning. This role has been discussed by numerous authors (e.g. Berger & Bostwick, 1994; Marshall & Kiemle, 2005; Querci della Rovere, 2004), however the current study's subcategories of parenting and employment have received very little attention in the literature. These findings can be seen to differentiate the present study from existing research in this area.

For example, while it is acknowledged that the loss of a breast can be devastating to a women's image of herself as a mother, there has been very little discussion of breast reconstruction's role in potentially re-establishing this. Steligo (2005)

proposes that children want to be reassured that their family and day-to-day life will be unchanged by illness and that parents should tailor the information provided, depending on the age and/or maturity of the child. The findings from this study suggest that breast reconstruction can aid women in this endeavour by allowing them to maintain a normal appearance and to exert some control over how their illness and treatment is presented to their children. This role has not been highlighted in the existing literature and so further exploration is recommended in future research.

With regards to the issue of employment, Steligo (2005) describes that “returning to work is a giant step on the road back to normal” (p.176) but notes that work colleagues may continue to view women as ‘ill’ for some time. The participants in this study suggested that reconstruction may help them to avoid this type of reaction by allowing them to be discreet about their treatment, if preferred. However, there appears to be a considerable dearth of research which discusses the role of breast reconstruction in helping to redress women’s identity in the workplace, despite this issue being highlighted as important for several women in this study. In a review of research into the relationship between employment and well-being, Waddell and Burton (2006) concluded that returning to work as soon as possible following illness is beneficial to health and overall well-being. While there are obvious financial gains, work is also seen to be central to one’s identity and status in a society where employment is the norm. Dodu (2005) describes that employment also offers the opportunity to boost one’s self-esteem and regain a sense of personal achievement. These goals were described as important to the women in the present study. The role

of breast reconstruction in relation to issues of employment is therefore suggested as suitable for future research.

4.2.2 Main Categories and Additional Findings

The present study identified a common theme from the participants that undergoing breast reconstruction was instrumental in allowing them to 'move on' from their cancer experience. In 'The Boudica Within' (Sassoon, 2007), Mary describes feeling in limbo prior to reconstruction:

"In time I gained confidence but whenever I saw myself in the mirror I was reminded. I was never able to move on". (p.90).

Other authors have noted the role of breast reconstruction in helping women to move forward (e.g. Neill et al., 1998; Nissen et al., 2002). Matheson and Drever (1990) suggest that by undergoing reconstruction, women make an assertion of their commitment to the future. Berger and Bostwick (1994) also describe that reconstruction can be a symbol of the finishing point of treatment and a sign from their surgeon that he is positive regarding the patient's likelihood of survival. Hamel (2007) reports feeling as though reconstruction has helped her to 'win the war':

"So the answer is yeah, I do feel like showing off my reconstructed breast. I've been through cancer, and my beautiful new breast feels like a symbol of survival. It's like wearing a military combat medal, but better; I don't have to take it off at night". (p.2)

And so, although not a life-saving procedure, Truelson (2003) suggests that breast reconstruction may be 'life-giving' for those women who feel unable to cope without

it, thereby integral to the process of rebuilding their self-image and move on. Being able to exert some control over their 'image of a sick person' was also identified in the present study as an important goal of reconstructive surgery. In 'The Boudica Within' (Sassoon, 2007), Lyndsey describes her need to take the power back from the disease:

"I knew instinctively I wanted a reconstruction and I wanted it done immediately. This proved to me the best part of the business. It was positive and I felt that I was taking control again, choosing what I wanted done – instead of being done to." (p.54)

Breast reconstruction's potential role in addressing the fear of cancer recurrence was also identified by the present study. This is supported by Graham (2000), who notes:

"Despite the individuality of mastectomy patients, I see remarkably similar motivations in their decision for breast reconstruction: the yearning for restoration of the female form, the emotional need to 'feel' like a woman, and the desire to suppress the fear of recurring breast cancer." (p.xiv)

It has been demonstrated that compared with women undergoing delayed procedures, women with immediate reconstruction report less fear of cancer (Filiberti et al., 1994). Nissen et al. (2002) describe how it is unrealistic to expect that breast reconstruction will help women to forget their breast cancer diagnosis, however if it is accepted that prostheses and/or mastectomy scars can act as reminder of cancer, then it is reasonable to suggest that undergoing reconstruction may help to manage, to varying degrees, an anxious preoccupation about cancer recurrence.

Further to the main data categories, the participants in this study highlighted some potential barriers to undergoing reconstruction. The literature suggests that it is common for women to face some opposition from others regarding surgery. In 'The Boudica Within' (Sassoon, 2007), Pearl describes:

"While I was waiting for the operation many friends and relatives who were afraid for me tried to convince me that I would be better off not going ahead with it. But I had made my decision, so I can honestly say that I went ahead with the reconstruction for me and me alone". (p.62)

In the same book, Mary recounts her story of the difficulties associated with accessing breast reconstruction services:

"...as soon as a mastectomy was mentioned I requested a reconstruction. I was however told to count myself lucky to be alive. Over the years I asked every new GP about a reconstruction. The response was always the same: 'Learn to live with it'." (p.90)

The ongoing National Mastectomy and Breast Reconstruction (MBR) Audit has reported initial findings that demand currently outstrips supply in relation to breast reconstruction surgery, particularly immediate surgery (NHS Information Centre, 2008). Crompvoets (2006) suggests that having to battle for the right to undergo reconstruction can sometimes results in women feeling a sense of failure or embarrassed at their inability to cope with mastectomy. However, this outcome was not described by the participants in the current study, which is perhaps testament to the support services involved.

4.2.3 *Further issues*

A number of additional issues were raised in the course of this research, concerning the social construction of women's self-image, sexuality, and hair loss. The first two of these issues were felt by the researcher to be notable by their absence. The latter issue was raised by a number of participants as important, but did not relate directly to breast reconstruction.

The Social Construction of Women's Self-Image

Despite Gimlin's assertion that "the body is a medium of culture" (2002; p.3), the women who participated in this project did not describe a significant influence of cultural or societal issues upon their decision to have breast reconstruction. While a mild degree of opposition from others was noted, it was not sufficient to stop them from having surgery. However, critics of breast reconstruction describe that women are often mistakenly led by others to believe that, if they do not undergo surgery, their mental health will suffer and their bodies will be 'defective' (Kasper, 1995; Wilkinson & Kitzinger, 1993). Truelson (2003) notes that a large proportion of the writing around breast reconstruction appears to be biased in its favour, for example describing the removal of a breast as a 'deformity'. It is suggested that language such as this could unduly influence women's choices regarding reconstruction.

Other feminist authors maintain that the attention given to cosmetic issues after mastectomy serves only to reinforce stereotypical attitudes towards women. Lorde (1997) writes that one's self-image can still be maintained without the use of prostheses or reconstructive surgery:

"We are told... our appearance is all, the sum total of self. I did not have to look down at the bandages on my chest to know that I did not feel the same as before surgery. But I still felt like myself, like Audre, and that encompassed so much more than simply the way my chest appeared." (p.58)

Lorde (1997) also suggests that the emphasis upon physical appearance following breast cancer surgery causes women to treat the loss of their breast as a secret, thus preventing the reclaiming of her self. Moderate support for this view can be gathered from the current study's finding that some participants underwent breast reconstruction partly so they could conceal their treatment from their children and work colleagues, for example. However, none of the participants saw this as restrictive, but reported instead that breast reconstruction gave them the freedom to regain their chosen self-image.

Sexuality

Marshall and Kiemle (2005) report that sexual relationships are typically resumed soon after breast reconstruction surgery, however women continue to experience post-operative sexual anxiety and changes. This can include loss of sexual desire and the sexual self. Partners also typically report anxiety about damaging the reconstructed breast, for example (Sandham & Harcourt, 2007). In the present study, there was very little mention of breast reconstruction's role in regaining or maintaining the participants' sexual self-image. At times during the interview process, the researcher suspected that participants wanted to discuss sexual matters in relation to reconstruction; however it appeared that they did not feel comfortable

enough to do so. As a result, the topic of sexuality sometimes felt like the 'elephant in the room' that went unacknowledged.

It is possible that this arose as a consequence of conducting only one interview; meaning that participants may not have felt relaxed enough with the researcher to introduce or discuss these issues in detail. However it is also possible that matters of sexuality were not foremost for participants. For example, Luker et al. (1996) found that information about the likely impact of breast cancer upon sexual attractiveness was not a priority for women during treatment. This topic requires further research in order to be better understood, particularly with women who are not in intimate relationships at the time of diagnosis and treatment.

Hair Loss

When discussing the impact of breast cancer upon appearance, the participants were noted to frequently mention the issue of hair loss (as a result of chemotherapy treatment), describing how damaging this could be to their sense of femininity also. One participant even considered losing her hair to be more distressing than the loss of her breast. Further, the participants felt that hair loss added to the 'image of a sick person' and was perhaps more difficult to conceal than their mastectomy. The psychological sequelae of chemotherapy-induced alopecia have been acknowledged in the relevant literature. For example, McGarvey et al (2001) describe that women with cancer who experience hair loss, compared with those who do not, report poorer body image and lower quality of life.

Further, Hansen (2007) found that women equated hair loss with the loss of womanhood, sickness and death. Rosman (2004) reports that rather than choosing to wear a wig in order to conceal their hair loss, some cancer patients will see their baldness as the symbol of a new identity. This description is similar to that of those women who choose not to wear a breast prosthesis or undergo reconstruction, preferring instead to incorporate their post-mastectomy appearance into their existing self-image. It is likely that the small literature base in this area would benefit from further research into the impact of hair loss upon women's self-image. The researcher has noted in clinical practice that hair re-growth following chemotherapy is also a common source of distress to women, due to changes in texture and colour, e.g. once straight hair can re-grow as curly. The implications of this change in appearance may be far-reaching and require further study.

4.3 Methodological Critique

A number of methodological limitations can be identified in relation to the current project. These can be grouped into the headings of 'Difficulties with the application of grounded theory methodology', 'Cultural factors' and 'Interviewing issues'. These project limitations will now be discussed in turn.

4.3.1 Difficulties with the Application of Grounded Theory methodology

Throughout the study, it was apparent that the researcher's inexperience with Grounded Theory methodology led to a number of implementation difficulties and dilemmas. This confirmed the assertion of Strauss and Corbin (1998), that in order

to do justice to the approach, researchers should undertake formal training prior to commencing a Grounded Theory project.

The first dilemma arose during the study's inception, in reference to the literature review. McGhee et al. (2007) describe that confusion over this stage of research is not uncommon. While Grounded Theory dictates that the formal literature review should be set aside until later in the process of analysis, it was necessary to explore some of the relevant literature in order to complete a research proposal form. Dallos and Vetere (2005) describe that the initial literature review should identify 'the [research] question as sitting within an under-theorised area, but does not proceed further at this stage' (p.55). They suggest that the main literature review should be driven by the emergent findings. However, Strauss and Corbin (1998) propose that researchers should not be barred from employing some deductive analysis, as influenced by existing theories. McGhee et al. (2007) suggest that "preknowledge should not prevent a grounded theory arising from the inductive-deductive interplay which is at the heart of this method" (p.340).

Ultimately, the researcher attempted to achieve a balance regarding this issue by reading widely on the topic of breast reconstruction, but did not read those articles and books which were likely to be highly relevant to breast reconstruction's role in women's self-image. Upon reading these texts following analysis, the researcher was able to feel confident that any shared emergent findings were representative of the data and had not been derived from preconceived ideas gathered from the literature.

A further difficulty in adhering strictly to the chosen methodology arose in the context of sampling. Grounded Theory requires that theoretical sampling techniques are utilised in order to develop theory and achieve a saturation of themes. However, the time constraints did not allow an open-ended period of recruitment and the available sample of women with breast reconstruction was small. This made it difficult to select each subsequent participant based upon their ability to add further insight to the emergent themes. It is therefore acknowledged that there was a limited capacity for theoretical sampling with this study.

Dallos and Vetere (2005) suggest that convenience sampling, whereby recruitment proceeds on the basis of availability, is acceptable when the participant pool is limited, such as with this study. The same authors also suggest that theoretical saturation is not just achieved through the sampling process, proposing that it can also be attained by adapting and tailoring the interview questions so as to maximise understanding of the phenomenon under study. With this technique, interesting theoretical leads can be explored within the available sample. And so while we cannot be certain if a true thematic saturation has been achieved in this study, it is perhaps acceptable to suggest that 'theoretical sufficiency' has been accomplished instead. This term is suggested by Dey (1999; 275) as more appropriate for use in Grounded Theory studies, as categories are produced not through exhaustive coding, but rather through partial coding. Dey posits that 'saturation' is an incongruent and imprecise expression which relies upon the researcher's inference that no more themes are to be found. In the present study, aiming for theoretical sufficiency

allowed a balance to be struck between the sampling methods appropriate to Grounded Theory and the availability of participants.

A further potential limitation of the study concerns bias which may have arisen in the sample. As women attending the support groups were asked to volunteer for the study, it is possible that only those who view reconstruction very positively may have agreed to take part. This could have biased the findings in favour of breast reconstruction. However, the purpose of the study was not to assess reconstruction as 'good' or 'bad', but to clarify the role it can play in relation to self-image, and so the effect of this bias is hopefully minimal. To clarify this issue, the Model of Breast Cancer, Breast Reconstruction and Self-Image could be tested further by exploring the experiences of women who have chosen not to undergo reconstruction, together with those who have been unhappy with the outcome of their reconstructive surgery. This could potentially identify, for example, alternative symbolic representations of survival, perhaps more enabling than breast reconstruction. Similarly, additional factors may be found which would alter the model's description of ways in which women refute the 'sick person' image.

Further, as women who have undergone breast reconstruction are a homogenous sample, there is a reduced ability to generalise the findings. However, as the model is firmly embedded in the context of breast cancer and reconstruction, it is unlikely that the findings would be of relevance to all women or all cancer sufferers, for example.

4.3.2 *Cultural Factors*

It is acknowledged that all of the breast reconstruction participants in this study were of the same ethnicity, culture and background. This makes it difficult for the findings to be generalisable beyond this cultural group. In order to address this, it is important that cultural issues are considered, for example women from different cultures or ethnicities may hold very different beliefs and meanings regarding not just breast reconstruction, but also in relation to the concepts of self-image or femininity. This issue has also been highlighted by Harcourt and Rumsey (2001), who describe a number of studies which have found cultural differences regarding attitudes to reconstructive surgery. For example, Kagawa-Singer, Wellisch & Durvasula (1997) found that breast reconstruction is less common with Asian American populations than with Anglo American. Similarly, Buis (2008) reports a low rate of reconstruction surgery in China, while Greenberg et al. (2008) suggest that socioeconomic status may be a stronger predictor of reconstruction uptake than ethnicity.

Again, while quantitative studies are informative, few studies have attempted to discuss these issues with women directly. Encouragingly, a qualitative study is currently underway at the Memorial Sloan-Kettering Cancer Centre in New York, examining decision-making regarding breast reconstruction in black and latina women⁵. Harcourt and Rumsey (2001) suggest that “If all women are to be helped to make informed decisions about breast reconstruction then it is important to consider the experiences of women from a range of ethnic and cultural backgrounds” (p.484).

⁵ See <http://clinicaltrials.gov/ct2/show/NCT00519974?term=Mammaplasty&recr=open&rank=3> (Pusic & Hurley, current research).

4.3.3 *Interviews and Retrospective Design*

There was very little discussion during the interviews about the participants' sexual relationships and the impact of breast reconstruction. It has been suggested that this may have been due to the participants being unwilling to bring this topic up at their first and only meeting with the researcher. Charmaz (2006) has suggested that single interviews may provide the researcher with only a shallow understanding of the participants' experiences. It is possible that having more than one interview would engender a greater rapport between interviewer and interviewee, thereby allowing a more in-depth and reflective discussion. However, conducting multiple interviews would have encountered the risk of participants entering into discussion, between interviews, with friends, family, or each other in a support group setting. This could have led to similar responses being heard from all participants, resulting in a reduced insight into the subject.

It is further possible that the interviews may have been affected by an imbalance in power common to clinical interviews. Participants may have been influenced by the researcher's position as a service provider and therefore may have provided responses that they felt the researcher was looking for, rather than a true reflection of their own experience. This potential acquiescence was hopefully minimised by the informal behaviour and dress of the researcher and by deferring to the participant as the 'expert' regarding breast cancer and reconstruction experiences.

A final limitation of this study can be seen in its use of a retrospective interview design. As stated previously, Harcourt and Rumsey (2001) have drawn attention to

the need for more prospective studies in this area of research and describe a number of difficulties associated with retrospective design. For example, one must consider the time that may have passed since surgery took place. Instead of accurately reflecting the feelings and concerns they experienced at the time of reconstruction, participants may have been influenced by their current thoughts on this issue, which could be very different.

4.4 Reflections on the Present Findings

4.4.1 *Participant reflections*

Dallos and Vetere (2005) suggest that qualitative research should allow the reader to hear not just the researcher's account of the phenomena in question, but also the participants' own voices. Following completion of the data analysis, it was therefore important to seek validation of the findings from those who took part. During brief telephone interviews with three randomly-selected participants, it was reflected that their involvement in the research had been a positive experience overall. One respondent described that she had enjoyed thinking back to the time of her reconstruction (8 years previously) and found that this confirmed for her that she made the correct choices at the time and would not do things differently now.

All three participants agreed that breast reconstruction had been key to 'feeling like me again', both in terms of appearance and day-to-day life. The core category and its subcategories were therefore strongly supported. Where respondents did not have personal experience of certain themes, e.g. employment at the time of reconstruction,

they were still able to comment on the findings due their involvement in support groups, which had given them a familiarity with other women's stories. Additional feedback regarding the 'Parenting' theme suggested that this should be applicable to grandparenting also, when the average age of women with breast cancer is considered. For example, one respondent described not wanting to appear 'different' to her grandson, to whom she is very close. The main categories were also seen to be an accurate reflection of the participants' narratives. It was suggested that when discussing breast reconstruction's role in signalling the completion of treatment, this should refer to the 'acute' stage of treatment, i.e. surgery and chemotherapy/radiotherapy. The respondents believed this differentiation was important when one bears in mind that treatment via medication can last for many years.

In summary, the respondent validation exercise generated good support for the present study's data categories and consequently the model of breast reconstruction and self-image.

4.4.2 Investigator reflections

In addition to gathering respondents' opinions on the validity of the study's findings, it is also important to be reflexive by recognising and exploring the potential influence of the researcher's assumptions and beliefs. By keeping a research diary, it was hoped that the existence of biased interpretation during data analysis would be minimised. This exercise was also valuable in prompting the researcher to consider her choice of research topic, while also acknowledging the emotions provoked by

working with participants who have experienced (and continue to experience) a devastating illness. For example, the first research diary extract below illustrates the researcher's thoughts regarding the possible reasoning for selecting to study breast reconstruction, instead of something perhaps more related to the negative aspects of facing a life-threatening disease:

"Breast reconstruction as a research topic was only decided upon following further reading and discussion – have I been motivated to choose this as it seemed like a 'safer' topic, with a focus on recovery rather than life-threatening illness?"

The next extract demonstrates that even with participants who were facing a recurrence of the disease, the prevailing tone of emotions generated during interviews was positive. This was somewhat contrary to what the researcher had expected:

"I was also surprised by the lack of upset, especially with the participant who reported that she now has a recurrence of cancer, having had 5 years in remission. I was struck by her ability to view her reconstruction surgery as positive... in fact her ability to be positive at all! Yet here she was, trying to help me understand what her experience had been like. The next interview was similarly upbeat, though happily has had no recurrence of the disease."

By exploring the researcher's personal frame of reference in a transparent fashion, it was possible to identify some areas of the analysis that may have been affected by professional experience. While not having personal experience of breast cancer and/or reconstruction, the researcher has worked clinically with individuals who do. It is acknowledged that in the majority of these cases, reconstruction is seen as a

healthy step and is easily accessible, with excellent support from the local Breast Care Team. Therefore it is possible that this prior experience may have influenced the researcher, when commencing the project, to view breast reconstruction in a very positive light. However, this assumption was not contradicted by the participants' narratives, as all agreed that they would absolutely recommend reconstruction to others. Indeed, even those participants who had experienced complications with their reconstruction remained pleased with their choice and expressed no regrets.

It is further possible that the identification of the 'Employment' theme may have been influenced by the investigator's previous experience of working as an occupational psychologist. The post in question was focused upon helping people to return to work following serious illness and was based upon the assumption that employment is beneficial to well-being and instrumental in helping one to build confidence and positive regard for the self. This could have potentially promoted an over-emphasis on the importance of employment to self-image following breast cancer, however it is felt, in conclusion, that the theme of 'Employment' grew fairly from the open coding process.

4.4.3 Clinical Implications

It is hoped that the model generated by the current research will be of relevance to clinical practice, particularly in relation to the decision-making process. Studies have revealed that women often find it difficult to decide whether or not to opt for reconstruction (e.g. Bremner-Smith et al., 1996; Fallowfield et al., 1994). This process can be particularly fraught when immediate reconstruction is an option, due

to there being little time available for deliberation. The findings of this study may contribute to women's ability to make an informed decision.

Harcourt and Rumsey (2001) report that women in this position should have contact with a trained professional, such as a specialist breast care nurse, who can guide them through the vast amount of information available. In order to address potential feelings of opposition to further surgery, it is also important that patients are encouraged to talk things over with their partner, family, friends and perhaps other women who have faced the same decision. Formal support networks, such as those from which this study's participants were drawn, are invaluable sources of real-life experience, both positive and negative.

The model presented in this study provides further information upon which women can base their decision about breast reconstruction. It helps to elucidate women's hopes and expectations for breast reconstruction, together with promoting a wider understanding of the changes that can occur to one's self-image following mastectomy. It offers clarification of the multi-faceted role that reconstruction can play in sustaining or re-establishing women's preferred image of themselves, illustrating that this role is not related only to normality of appearance and improved body image, but also encompasses a sense of normality in other aspects of the self. For example, prior to mastectomy, women may not be aware of the distressing effect this may have upon their image of themselves in the workplace (or other settings). The Model of Breast Cancer, Breast Reconstruction and Self-Image suggests that

breast reconstruction may offer a potential resolution to this distress by allowing women a greater degree of privacy surrounding their illness and treatment.

Support services with staff such as clinical psychologists and clinical nurse specialists may be particularly well suited to offering women the opportunity to explore their feelings about possible changes to their self-image following mastectomy.

4.5 Final Thoughts

This study has explored the role of breast reconstruction in relation to women's self-image following mastectomy for the treatment of breast cancer. The findings add to the existing literature by highlighting that the function of breast reconstruction is somewhat wider and more subtle than may have previously been thought, reaching beyond women's feelings about their appearance and into their view of themselves as a feminine and whole woman, a parent, a 'sick person' and in the workplace. Breast reconstruction was also found to play a significant role in enabling women to gain control and move on from their breast cancer experience. When taken together, the various outcomes of breast reconstruction allow women to reconstruct their self-image and 'feel like me again':

"I would say it's helped me..., helped me heal in all senses, you know... It's helped me work things out emotionally, physically, mentally... to be me." (Pt 1)

While the findings of this study were overwhelmingly in favour of breast reconstruction, it should be emphasised that deciding whether to have breast reconstruction or not is very much an individual choice, and this research should not suggest that it should be undertaken in 100 per cent of cases. Several authors have proposed that there is evidence in support of women being able to adapt to their changed image and resume normal functioning without reconstruction (e.g. Reaby et al., 1994; Kasper, 1995), thus care should be taken not to coerce women into electing for surgery. Similarly, the researcher does not wish to suggest that women have no option but to “seek....a lifetime of disguise” through undergoing reconstruction (Wilkinson and Kitzinger, 1993; 231) or that they should hide the loss of the breast “as if it were the result of some crime of which she were guilty” (Lorde, 1997; 58). While it is unfortunate that some women feel unable to cope without reconstruction, regardless of the reasons for this, it would surely be unethical to deny women the option of reconstruction just because their desire for it may or may not be socially constructed.

In conclusion, the present study’s findings indicate that reconstruction can be empowering and liberating for women, freeing them from the need to cover up and alter their image of themselves. With further testing and development, it is hoped that the model presented in this study will contribute to a growing literature base on women’s experiences of breast cancer and breast reconstruction surgery.

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APPENDICES

APPENDIX A

PARTICIPANT INFORMATION SHEET

Introduction

Thank you for agreeing to read this information sheet. I am a Trainee Clinical Psychologist with the Health Specialty of the Clinical Psychology Department at Stratheden Hospital. I would like to invite you to take part in a research project, entitled **The Impact of Breast Reconstruction Following Mastectomy Upon Women's Self Image**. This study is being carried out as part of the Doctorate in Clinical Psychology qualification at the University of Edinburgh. Agreement for the study has been obtained from _____ and _____ of the Breast Care team.

Before you decide if you would like to participate further, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following and feel free to get in touch with me if there is anything you are unclear about or if you have any questions.

What is the study about?

A small body of research has examined how breast reconstruction surgery affects women's feelings about themselves, i.e. their 'self-image'. Self-image can be seen to include issues of femininity and feelings about one's identity, as well as the physical body. It is thought that a need to feel womanly is one reason that women may undergo breast reconstruction, but we do not know what women really think about themselves in this situation. Furthermore, very little is known about the impact that reconstructive surgery may have on a person's ability to adjust to their diagnosis of breast cancer.

One way of learning more about this is to carry out interviews to explore women's thoughts and feelings in depth. This study will focus particularly upon how breast reconstruction following a diagnosis of breast cancer may affect how women view themselves (self-image and identity), both in terms of the changes to their body and also to their place in their family and other groups (social roles).

The Fife and Forth Valley Research Ethics Committee, which has responsibility for scrutinising proposals for medical research on humans, has examined this proposal and has raised no objections from the point of view of medical ethics.

Why have I been asked to take part?

You have been invited to participate as you have been given a diagnosis of breast cancer in the last few years, the treatment of which involved a mastectomy and breast reconstruction. You may feel that it would be useful to discuss how this may have changed how you see yourself.

Do I have to take part?

It is your decision whether you decide to take part or not. Participation is entirely voluntary and you can choose not to take part if you so wish. If you feel that this research could be of interest to you, please fill out the reply slip enclosed and return it to the address shown on the envelope provided. You will then be asked to sign a consent form which indicates that you have read and understood this information and that you consent to being interviewed for research purposes.

You are free to withdraw from the study at any time and you do not have to give a reason for this, even if you previously agreed to take part. If you decide not to take part or to withdraw, this will not affect your access to any services in the future.

What will I be asked to do?

If you decide to take part in this study, you will be contacted in order to arrange a convenient time and place to meet for the interview. This is likely to be at the beginning of April. The interview can be carried out at your home, or in a private room at one of 3 locations: Victoria Hospital, Kirkcaldy; Queen Margaret Hospital, Dunfermline; or Stratheden Hospital, Cupar. The interview will take no longer than 1 hour and will be recorded. Recordings will be transcribed soon afterwards and then destroyed.

The interview questions will focus on the experience of having breast cancer and undergoing breast reconstruction surgery. Here are some examples:

- *Can you describe the effect that undergoing breast reconstruction had?*
- *How did your breast cancer diagnosis affect how you saw yourself? Has undergoing breast reconstruction addressed some (or all) of this?*
- *What challenges have you faced and how have you tackled them?*
- *Does the media, e.g. magazines and TV, have an effect on your view of yourself?*

Unfortunately, travel expenses will not be provided to those taking part due to budgetary limitations. However, every effort will be made to minimise the financial costs to participants.

Are there any risks/benefits to taking part?

It is hoped that this study will benefit you as you will be provided with the opportunity to discuss issues which are often overlooked during the recovery from breast cancer. You do not have to share any information that you do not wish to. There should be no risks associated with taking part. However, you can stop the interview at any time should you wish to.

If taking part in the interview is very upsetting to you in the following days or weeks, you will be offered an appointment with a psychologist from the Clinical Psychology

Health Specialty. If at any time you wish to make a complaint about any aspect of the research, you can do so by following the normal complaints procedure through the Patient Relation Department, Hayfield House, Hayfield Road, Kirkcaldy, KY2 5AH (Tel: 01592 643355, ask for extension 8787).

Confidentiality

All information collected during this study will be kept strictly confidential. It will be stored securely on NHS property for 5 years after the study has been completed and the only people to have access to it will be myself and my research supervisors. Any identifying information will be removed so that it is anonymous. Direct quotations may be included in the final report of this study but only if there is no possibility of the person making the quote being identified as a result.

With your permission, your GP will be informed of your participation in this study.

Results of the research study

If requested, a presentation on the main research findings will be offered to participants. Written feedback will also be available if preferred. The findings of this study may be shared with other professionals to increase and contribute to the understanding of self-image issues in breast cancer settings. However, participant names will not be used and you will not be identified in any publication resulting from this study. Your opinions and experiences may also help further develop the services that breast cancer patients receive in Fife in the future.

If you require more information or have a specific question about the research, I would be happy for you to contact me or my research supervisor, _____, on _____ or contact your breast care nurse on _____.

Thank you again for taking the time to read this information.

Best wishes,

Ms Lindsay McKean
Trainee Clinical Psychologist

**Dept of Clinical Psychology
Stratheden Hospital
Cupar
KY15 5RR**

Tel: _____
Email: _____

Reply slip

I would like to take part in this study

☐

Name: _____

Address:

Telephone number Home: _____

Mobile: _____

Email: _____

What is the best way to contact you?

Please return this form in the envelope provided as soon as possible.
Alternatively, please contact me by telephone on _____. If you are unable to reach me, please leave your contact details with the secretary or on the answering machine and I will get back to you as soon as possible.

APPENDIX B

Fife, Forth Valley & Tayside Research Ethics Service

Fife & Forth Valley Research Ethics Committee

Research Ethics Office

Level 9

Ninewells Hospital & Medical School

DUNDEE

DD1 9SY

Ms Lindsay McKean
Trainee Clinical Psychologist
NHS Fife
Dept of Clinical Psychology
Stratheden Hospital
CUPAR KY15 5RR

Date: 18 March 2008
Your Ref:
Our Ref: FB/RH/08/S0501/20
Enquiries to: Miss Fiona Bain
Extension: Ninewells extension 32701
Direct Line: 01382 632701
Email: fionabain@nhs.net

Dear Ms McKean

Full title of study: The impact of breast reconstruction following mastectomy upon women's self-image: A grounded theory approach
REC reference number: 08/S0501/20

Thank you for your letter of 17 March 2008, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The favourable opinion applies to the research sites listed on the attached form.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Application		23 January 2008
Investigator CV		23 January 2008
Protocol	3	23 January 2008
Covering Letter		24 January 2008
Letter from Sponsor		28 January 2008
Compensation Arrangements		20 July 2007
Interview Schedules/Topic Guides	3	23 January 2008
Participant Information Sheet: Staff	4	14 March 2008
Participant Information Sheet: Participant	4	14 March 2008
Participant Consent Form: Staff	4	14 March 2008

Document	Version	Date
Participant Consent Form: Participant	4	14 March 2008
Response to Request for Further Information	Email	17 March 2008
Cover Letter to Sponsor Letter, Ms M Bucukoglu		28 January 2008
Signature of Sponsor (Ms M Bucukoglu)		28 January 2008
Letter of Support, Mrs A Fernon		10 December 2008
Reply Slip	3	21 January 2008
CV, Dr E F Newman		

R&D approval

All researchers and research collaborators who will be participating in the research at NHS sites should apply for R&D approval from the relevant care organisation, if they have not yet done so. R&D approval is required, whether or not the study is exempt from SSA. You should advise researchers and local collaborators accordingly. Guidance on applying for R&D approval is available from <http://www.rdforum.nhs.uk/rdform.htm>.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

Here you will find links to the following

- Providing feedback. You are invited to give your view of the service that you have received from the National Research Ethics Service on the application procedure. If you wish to make your views known please use the feedback form available on the website.
- Progress Reports. Please refer to the attached Standard conditions of approval by Research Ethics Committees.
- Safety Reports. Please refer to the attached Standard conditions of approval by Research Ethics Committees.
- Amendments. Please refer to the attached Standard conditions of approval by Research Ethics Committees.
- End of Study/Project. Please refer to the attached Standard conditions of approval by Research Ethics Committees.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nationalres.org.uk.

08/S0501/20	Please quote this number on all correspondence
--------------------	---

Yours sincerely

Mr Gavin Costa
Chair

Enclosures: Standard approval conditions (SL-AC2)
 Site approval form

Copy to: Ms Marise Bucukoglu
 Associate Director
 Edinburgh Clinical Trials Unit
 47 Little France Crescent
 EDINBURGH EH16 4TJ

Ms Aileen Yell, NHS Fife R&D Office

APPENDIX C

Participant Consent Form

Project Title: *The impact of breast reconstruction following mastectomy upon women's self-image.*

Researcher: Ms Lindsay McKean, Trainee Clinical Psychologist

Participant Identification Number:

Thank you for agreeing to be interviewed for this project. I would be grateful if you could read the information below and sign if you are happy to proceed.

1. I confirm that I have read and understand the information sheet dated..... (version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

Please
tick box

☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

☐

3. I agree that my GP is informed of my participation in this study.

☐

4. I understand that the interview will be recorded for the purposes of analysis and the recording will be destroyed immediately following transcription.

☐

5. I agree that direct quotations may be used in reporting the results of this study, provided they do not identify the participant in question.

☐

Signed: _____

Date: _____

Print Name: _____

Consent taken by: _____

APPENDIX D

GP
Address

Dear Dr _____,

Re: Participant

I am writing to inform you that the above patient has agreed to take part in a research project entitled 'The impact of breast reconstruction following mastectomy upon women's self-image'. This study is being carried out as part of my Doctorate in Clinical Psychology qualification at the University of Edinburgh, under the clinical supervision of _____, Consultant Clinical Psychologist. Agreement for the study has been obtained from _____ and _____ of the Breast Care team and recruitment has been facilitated by _____ and _____, Breast Care Nurses. The Fife and Forth Valley Research Ethics Committee has examined this proposal and has raised no objections from the point of view of medical ethics.

Participation in this project involves a one hour single interview, which will focus upon the experience of having breast cancer and undergoing breast reconstruction surgery. It is possible that participants may be identified who have clinical levels of anxiety or depression. If this is the case, the participant will be offered an appointment and appropriate follow-up with a psychologist from the Clinical Psychology Health Specialty. Support from the researcher will also be offered to those who may find the interview process upsetting.

Please do not hesitate to contact me if you have any queries.

Yours sincerely,

Trainee Clinical Psychologist

APPENDIX E

SEMI-STRUCTURED INTERVIEW SCHEDULE

Research Question 1: How does the experience of breast reconstruction surgery affect women's views of themselves?

Prompts

Tell me about when you were diagnosed with breast cancer...

What factors were important to you when deciding whether or not to have breast reconstruction?

Can you describe the effect that undergoing breast reconstruction had? Were your expectations met? What areas of life has it made a difference to, e.g. family; marital relationship; work; friends?

Research Question 2: What role does reconstruction play in addressing and overcoming the challenges of day-to-day life following a diagnosis of breast cancer?

Prompts

In the type of situation that you have experienced, some women approach challenges in different ways. What challenges have you faced and how have you tackled them?

How is support from others important in this?

Research Question 3: What role does reconstruction have to play in adjusting to breast cancer and illness experience?

Prompts

How would you have felt if your reconstruction surgery had been delayed, or not offered at all? Do you see breast reconstruction as being a part of the treatment for breast cancer?

How did your breast cancer diagnosis affect how you saw yourself? Has undergoing breast reconstruction addressed some (or all) of this?

Do you have a view on the type of support that should be provided for women who have been in your position?

Research Question 4: What additional meaning, if any, does breast reconstruction hold for women?

APPENDIX F

Not very many women get that option I think, because most of them do get radiotherapy, so I did, I did just think "Oh, go on then" (LAUGHS), do you know, 'Go on then'... It didn't really matter to me so much..., although waking up from the operation..., that would have been a lot more traumatic, had I not had the reconstruction done. In hindsight, it was pretty massive, you know the difference I think, having the reconstruction, waking up from an operation like that, and still having a breast as such, and waking up and not having anything, I think that probably psychologically would have been pretty major for me.

Interviewer: Right, ok. So you look back now and you think, you're quite pleased that you got...

Participant: I'm SO happy...

Interviewer: ...that done at the time

Participant: ...that I had it done, and I'm so happy that I had the option to get it done at the time.. em.. I think it made the whole thing easier for me, in that when I woke up from the operation, em.. it's quite scary to think you've not got a breast anymore, but the way that {Breast Surgeon} does it, is he puts a clear dressing on [Right] and it's just a little bit of tape round the scar, white tape, so you can actually see it [Right] ... There's not this big unveiling [Ah, I didn't know that..] , which was.. and I, I actually wrote to him and said that, you know 'This is a brilliant idea', because I think it would have been scarier has it been all covered up and

Others don't have the choice,
Lucky
Go on then, why not?
Taking a chance

Traumatic
Benefit of hindsight
Made a massive difference

After the operation
Still has breast vs. no breast
Major psychological implications

Able to reflect...

HAPPY about recon

Happy with IMMEDIATE RECON
Made it easier

Scary waking up -
Loss of breast

Not so scared
Clear dressing
Important to see

Not the unknown

Action - wrote letter
Covered up = scary

there was a big unveiling of these bandages, you know, “What’s it gonna look like..?”, whereas you could actually see...

Interviewer: Straightaway, no delay...

Participant: ..most of it... And even em.. cos I’ve spoken to women that have had mastectomies without reconstruction, similar kind of thing, it is a lot easier if you can kinda see it, straightaway, on your own, havin’ a wee sneaky peek without this big drama if you like.

Interviewer: Uhuh. So what was the sort of time frame then between diagnosis and having that surgery?

Participant: Now... diagnosis would be... you’re probably talking.. maybe 3 weeks, maybe 2, 3, 4 weeks to get the lumpectomy, and then we went to Centreparcs for a week, and you’re probably talking maybe another 2, 3 weeks [*Right, ok*] to go back an get the mastectomy, and then obviously another few weeks before I started chemotherapy [*Right, ok*] ... It’s hard to remember now...

Interviewer: Yeah, it must be...Ok. And so you talked about making that decision and you were looking for, at the time you would quite like somebody to say ‘Do this’ or ‘Do that’... You spoke with your husband and with others...?

Participant: Yes, em... I didn’t have the luxury of speaking to, I don’t think, somebody that actually had

Need questions to be answered...

Not hidden

Talking to others

Important not to have delay when seeing the first time.
No drama

Timing of surgery

Time from diagnosis until surgery
Approximate
Timeline of surgery
Lumpectomy
holiday

mastectomy
chemo
hard to remember
details

Taking advice from others to make decision?
Influence of husband?

Speaking to others with RECON is a luxury

the reconstruction, which em.. I've done since then with other ladies at the group and the hospital [*Yep, uhuh*] and I think that definitely kinda helps, seeing it in the flesh, if you like, cos photographs don't really... em.. and speaking to somebody that's been through it and done it, definitely would help, em... But I think the age thing was 'Right, I'm still young'.. I wanted to get my life back... I thought it would probably enable me to have more of a normal life, and again in hindsight, I know friends that have had delayed reconstruction, and they're so grateful that they've had the chance to do that..., they don't have to put this thing in their bra every morning, it's a constant reminder...

Interviewer: So they've noticed that, that difference [*Absolutely*] in that before they've had it done...

Participant: And even what you can wear.., I mean I can wear as low tops as I did before, whereas if you've not had it done, you're quite restricted cos I think it can come up quite high and you can see it, you know... [*Ok*] So...em.. like I say, the main, the main decision was (PAUSE), it wasn't a decision, it was to get the cancer out first, and whatever after that came as a bonus if you like.

Interviewer: Ok... and yeah I suppose for you at the time, so it happened sort of, as you say, as a bonus, almost incidentally to the rest of the treatment, or the, what was happening at the time...

Sharing with others
Communication
Helpful to see in the flesh
Real examples – learn from others who have been through it

Age important
RECON helps gets life back
NORMAL life
Delayed recon very positive also

Takes away need for prosthesis – reminder of difficult times / events

Reasons for RECON

What you can wear
Low tops – AS BEFORE
Restricted if no RECON
Can't control what to show

Getting rid of cancer is priority
RECON = bonus

RECON as a bonus

Participant: And I was also lucky I had no real problems, because another fear I had was that I was gonna have all this done and it wouldn't take for some reason [Right] em.. and I'd end up losing the implant and I'd gone through all that for nothing, I'd a scar on my back and not end up having a boob, you know so... em... I was pretty lucky that it went well, you know..., and I've since had the other breast removed [Right] ... had a, is it prophylactic mastectomy you call it [Yep] and the reconstruction done on that side as well [Right, ok] so em... that made me feel a little bit better...

Interviewer: Was that at the same time as well?

Participant: No, that was about a year later, em.. I think it was recommended at the time that it would be an option maybe later on, just because of the type of cancer that I had and the age I was, and I always remember 'Right, ok, as soon as I can get it done, I'm wanting it done, then', you know, rather than wait, and something maybe happen, just do it, cos I think once..., if you've not got 1 breast it doesn't matter if you've not got 2... 1 or... it doesn't make any difference [Ok] you know, so, I might as well... makes them even...

Interviewer: And is there a family history, or, I was wondering if ..., I mean did you have any prior experience or met anybody who'd had breast cancer before?

Participant: No, none whatsoever. I don't know where it's come from... and that's always a big, big question why, what caused it, I've read books...

Lucky to have no problems
Fears about recon – it won't work
It won't take
Will lose implant
Might go through it all for nothing
Might end up worse off
Good experience – so had preventative mastectomy on other breast

Helped to feel better

Timing?

2nd recon delayed recommended – due to type of cancer and age

Get it done ASAP why wait....?
Something bad might happen

Loss of 2 breasts no different to 1

Makes them even

Prior experience of cancer..?

No prior experience of BC
Where has it come from..?
Searching for answers

Interviewer: Somebody else was saying earlier about, you know, other cancers have a more, sometimes there's a clear, you know if you smoke a lot..., lung cancer or whatever, but breast cancer there isn't really anything like that...

Participant: And there's so many different types as well and I've spoken to so many different women that don't drink, that don't eat meat, that don't eat dairy and they still had breast cancer [Yep], you know cos these are all questions that I've, I've asked myself and changed my diet and em.... there's no answer is there? Which is pretty frustrating, and even just the different types that you get, and the whole Herceptin thing and oh you know, there's loads of things going on in your head...

Interviewer: Ok then. Ah... right, so let me just make sure that I've answered this wee bit, so when it came to deciding about the breast reconstruction, em.. any other factors that were important... so you were thinking about your age and what was ahead of you, your son...,

Participant: Husband as well...

Interviewer: ...what you would want to do... husband as well...

Participant: Yeah, you know I mean it's a major thing in your marriage to, to go through, and I just thought well it might make me feel better about myself and hence.. I mean my husband's been terrific and I

Cause of BC often unknown...

So many different types
Very CONFUSING
What causes it?

Questions

Lifestyle changes
No answer –
frustrating
Herceptin - drugs

Overloaded with thoughts
CONFUSION

Other factors
important to recon?

Husband

Major event in marriage
Feel better about self
Helps marriage in turn

know what he's like, it really wouldn't..., he says it wouldn't bother him and I know it really really wouldn't, em.. but you know what it's like..., If it bothers you then you start not wanting to get undressed, or being naked in front of them, or...it could have huge repercussions sexually, so I did it for that as well, you know...

Interviewer: So, although you, that actually hadn't happened because this was sort of all prior to the surgery, but your expectations were, was there that that could have happened... [Yeah] . Ok... and other family, did you speak with other family members, friends?

Participant: Em... I'm a very open person, so yeah, you know I spoke to all my friends, my mum, my sister, em.. because I always made everybody feel my lump before it got taken away, 'Now look, this is cancer, so just get checking...', em... and they were all just, 'Whatever you want to do..', but em... I didn't ever really think 'Will I or won't I?'... It pretty much was 'I think I will'. Em.. the only worry was that it wasnae gonnae take, that was my main thing, but em.. they were all very supportive and...

Interviewer: And you would recommend it to others then would you?

Participant: Absolutely, 100%... but then again, like I said I haven't had any problems, em.. other than maybe a wee bit of back problems... getting out my chair, or a pool's quite hard now, em... but...,

Trust in husband – it won't bother him

But still matter in case it bothers me...
Getting undressed
Being naked in front
Expects that would be difficult without RECON
Expectation that would be distressed and impact on marriage if didn't have RECON

Other support

Open / communication
Female support
Encouraged others to check
Learn from events

Others supportive of RECON
Always positive, but worried that might not take

Family supportive

Recommend?

Definitely recommends, though aware had no problems
Some after-effects but worth it
Totally recommends

APPENDIX G

Reconstruction.mvp - NVivo

File Edit View Go Project Links Code Tools Window Help

New Open Recent Save Undo Redo Cut Copy Paste Find Sort By

Code At

Nodes

Free Nodes

Tree Nodes

Cases

Relationships

Matrices

Search Folders

All Nodes

Look for:

Search In

Free Nodes

Find Now

Clear

Free Nodes

Name	Sources	References	Created On	Modified On	Created By	Modified By
Loss (of breast)	4	15	10/06/2008 22:26	20/06/2008 19:28	LM	LM
Lust for life	4	6	09/06/2008 18:12	20/06/2008 19:24	LM	LM
Marriage	7	29	07/06/2008 11:22	21/06/2008 12:41	LM	LM
Media influence	4	10	09/06/2008 18:28	20/06/2008 16:39	LM	LM
Mother role	6	34	09/06/2008 17:14	21/06/2008 16:09	LM	LM
Moving on	8	39	21/06/2008 18:57	21/06/2008 18:57	LM	LM
Nipples	6	7	09/06/2008 18:16	20/06/2008 19:24	LM	LM
No recon	4	8	15/06/2008 16:05	21/06/2008 16:06	LM	LM
Normal appearance	10	89	07/06/2008 11:03	21/06/2008 16:06	LM	LM
Normal life	9	54	07/06/2008 11:13	21/06/2008 16:06	LM	LM
Normal self	10	57	09/06/2008 18:17	21/06/2008 16:06	LM	LM
Opposition to recon	5	11	15/06/2008 15:35	21/06/2008 16:06	LM	LM
Parenting	2	3	06/06/2008 12:25	16/06/2008 18:41	LM	LM
Physical impact	4	7	09/06/2008 18:33	20/06/2008 19:27	LM	LM
Pre-recon body	6	32	09/06/2008 18:31	21/06/2008 13:14	LM	LM
Prosthesis	10	33	07/06/2008 11:14	21/06/2008 16:06	LM	LM
Psychological benefit	9	92	10/06/2008 22:23	21/06/2008 16:06	LM	LM
Reasons for recon	2	2	15/06/2008 16:14	16/06/2008 18:41	LM	LM
Recommendations	4	7	09/06/2008 17:08	21/06/2008 13:20	LM	LM
Recon as a life saver	3	3	07/06/2008 11:00	20/06/2008 19:24	LM	LM
Recon as part of treatment	10	49	21/06/2008 18:57	24/07/2008 12:28	LM	LM
Recon not a cure all	4	14	16/06/2008 18:23	20/06/2008 19:24	LM	LM
Reminders of cancer	6	24	15/06/2008 18:23	21/06/2008 16:06	LM	LM
Sick appearance or role	7	30	15/06/2008 18:12	21/06/2008 16:08	LM	LM
Support from others	9	28	09/06/2008 18:39	21/06/2008 16:08	LM	LM
Surviving	8	29	09/06/2008 18:46	21/06/2008 12:41	LM	LM
Type of recon	1	1	15/06/2008 18:20	16/06/2008 18:41	LM	LM

Sources

Nodes

Sets

Queries

Models

Links

Classifications

Folders

LM 58 items

Welcome Center

Reconstruction.mvp ...

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WVivo images - Mic...

12:02

Reconstruction.nvp - NVivo

File Edit View Go Project Links Code Tools Window Help

New

Open

Save

Print

Find

Find Next

Find Previous

Find All

Find in Selection

Find in Project

Find in Code

Find in Links

Find in Tools

Find in Window

Find in Help

Find in Project

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Look for:

Search In

Free Nodes

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Nodes

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Tree Nodes

Cases

Relationships

Matrices

Search Folders

All Nodes

Free Nodes

Name	Sources	References	Created On	Modified On	Created By	Modified By
Use of work to cope	1	1	10/06/2008 22:33	15/06/2008 16:04	LM	LM
Wholeness	4	12	19/06/2008 18:30	21/06/2008 12:41	LM	LM
Womanliness	7	36	10/06/2008 22:29	21/06/2008 13:14	LM	LM
Work and recon	7	31	19/06/2008 15:49	24/07/2008 12:39	LM	LM

Sources

Nodes

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Welcome Center

APPENDICES

Reconstruction.nvp ...

NVivo images - Mic...

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APPENDIX H

PARTICIPANT INFORMATION SHEET - STAFF

Introduction

Thank you for agreeing to read this information sheet. I am a Trainee Clinical Psychologist with the Health Specialty of the Clinical Psychology Department at Stratheden Hospital. I would like to invite you to take part in a research project, entitled **The Impact of Breast Reconstruction Following Mastectomy Upon Women's Self Image**. This study is being carried out as part of the Doctorate in Clinical Psychology qualification at the University of Edinburgh.

Before you decide if you would like to participate further, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following and feel free to get in touch with me if there is anything you are unclear about or if you have any questions.

What is the study about?

A small body of research has examined how breast reconstruction surgery affects women's feelings about themselves, i.e. their 'self-image'. Self-image can be seen to include issues of femininity and feelings about one's identity, as well as the physical body. It is thought that a need to feel womanly is one reason that women may undergo breast reconstruction, but we do not know what women really think about themselves in this situation. Furthermore, very little is known about the impact that reconstructive surgery may have on a person's ability to adjust to their diagnosis of breast cancer.

One way of learning more about this is to carry out interviews to explore women's thoughts and feelings in depth. This study will focus particularly upon how breast reconstruction following a diagnosis of breast cancer may affect how women view themselves (self-image and identity), both in terms of the changes to their body and also to their place in their family and other groups (social roles).

I am going to carry out a number of one-to-one interviews with women who have undergone breast reconstruction surgery. I would like to follow this up by conducting a focus group with members of the Breast Care team. The Fife and Forth Valley Research Ethics Committee, which has responsibility for scrutinising proposals for medical research on humans, has examined this proposal and has raised no objections from the point of view of medical ethics.

Why have I been asked to take part?

You have been invited to participate as you are a member of the Breast Care team and therefore work on a daily basis with breast cancer patients. I am interested in

exploring your thoughts about the impact of breast cancer and breast reconstruction surgery upon women's self-image. You may have discussed these issues with patients during the surgery decision-making process, for example.

Do I have to take part?

It is your decision whether you decide to take part or not. Participation is entirely voluntary and you can choose not to take part if you so wish.

When we meet for the focus group, you will then be asked to sign a consent form which indicates that you have read and understood this information and that you consent to being interviewed for research purposes. You are free to withdraw from the study at any time and you do not have to give a reason for this, even if you previously agreed to take part.

What will I be asked to do?

If you decide to take part in this study, you will be contacted in order to arrange a convenient time and place to meet for the interview. This is likely to be at the end of May. The interview will take approx. 30 minutes and will be recorded. Recordings will be transcribed soon afterwards and then destroyed.

The interview questions will focus on your views about the experience of undergoing breast reconstruction surgery following a diagnosis of breast cancer. Here are some examples:

- *How do you think a breast cancer diagnosis affects how women see themselves?*
- *Do you think that undergoing breast reconstruction addresses some (or all) of this?*
- *What factors are important to you regarding breast reconstruction surgery?*

Are there any risks/benefits to taking part?

It is hoped that this study will benefit you as you will be provided with the opportunity to discuss issues related to breast reconstruction, an area which is somewhat under-researched. You do not have to share any information that you do not wish to. There should be no risks associated with taking part. However, you can stop the interview at any time should you wish to. If at any time you wish to make a complaint about any aspect of the research, you can do so by following the normal complaints procedure through the Patient Relation Department, Hayfield House, Hayfield Road, Kirkcaldy, KY2 5AH (Tel: 01592 643355, ask for extension 8787).

Confidentiality

All information collected during this study will be kept strictly confidential. It will be stored securely on NHS property for 5 years after the study has been completed and the only people to have access to it will be myself and my research supervisors. Any identifying information will be removed so that it is anonymous. Direct quotations may be included in the final report of this study but only if there is no possibility of the person making the quote being identified as a result. This is particularly important due to the small number of staff taking part.

Results of the research study

If requested, a presentation on the main research findings will be offered to staff. Written feedback will also be available if preferred. The findings of this study may be shared with other professionals to increase and contribute to the understanding of self-image issues in breast cancer settings. However, participant names will not be used and you will not be identified in any publication resulting from this study. Your opinions and experiences may also help further develop the services that breast cancer patients receive in Fife in the future.

Contact details

If you require more information or have a specific question about the research, I would be happy for you to contact me or my research supervisor, _____, on _____.

Thank you again for taking the time to read this information.

Best wishes,

Ms Lindsay McKean
Trainee Clinical Psychologist

Dept of Clinical Psychology
Stratheden Hospital
Cupar, KY15 5RR
Tel: _____
Email: _____

Reply slip

I would like to take part in this study

☐

Name: _____

Work Address:

Telephone number Work: _____

Mobile: _____

Email: _____

What is the best way to contact you?

Please return this form in the envelope provided as soon as possible.
Alternatively, please contact me by telephone on _____ or by
email at _____. If you are unable to reach me, please leave
your contact details with the secretary or on the answering machine and I
will get back to you as soon as possible.

Participant Consent Form - Staff

Project Title: *The impact of breast reconstruction following mastectomy upon women's self-image.*

Researcher: Ms Lindsay McKean, Trainee Clinical Psychologist

Participant Identification Number:

Thank you for agreeing to be interviewed for this project. I would be grateful if you could read the information below and sign if you are happy to proceed.

Please
tick box

1. I confirm that I have read and understand the information sheet dated..... (version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

☐

3. I understand that the interview will be recorded for the purposes of analysis and the recording will be destroyed immediately following transcription.

☐

4. I agree that direct quotations may be used in reporting the results of this study, provided they do not identify the participant in question.

☐

Signed: _____

Date: _____

Print Name: _____

Consent taken by: _____

APPENDIX J

14.01.08

Planned recruitment method changed. Original method was to get breast care nurses to select potential participants from database, contact and establish if interested in taking part. If so, details would be passed onto researcher. However, breast care nurses understaffed and unable to assist in recruitment to this degree. Nurses suggested instead recruiting through existing support groups, introduced by nurses to group, brief presentation and hand out PIS to those who meet inclusion criteria. Attached will be an opt-in reply slip with stamped addressed envelope, for ease of return. Consent forms will be signed at the time of interview.

Initially reluctant to change methods, but glad this was mentioned by nurses, as it makes sense both in terms of ethical considerations and time resources.

05.02.08

Planning and background reading continues. The more I read about Grounded Theory, the more I wonder if I'm doing the right thing! But I am reminded of Richards' (2005) description of qualitative research... "Observation and communication in almost any research (or life) situation will provide huge quantities of information. We turn the information into 'data' when we record it and try to make sense of it. It becomes relevant data, evidence for our arguments, when its relationship to a research question is established".

Theory... Richards' (2005) - theories come in all shapes and sizes. Our everyday life is informed by theories... little, local theories are usually the goal of qualitative research.

04.03.08

Attended ethics meeting today – me versus 21 committee members! Should undertaking research be this difficult? Felt a bit like I was on trial or that they were trying to catch me out. But at the same time it's important to consider why I'm doing this project and how it's going to benefit those taking part.

The meeting has also encouraged me to consider my reasons for doing this project. Discussion with colleagues led me to look into breast cancer as a potential research topic. I cannot claim to be personally invested in this area of study as I don't have a family history of breast cancer, nor have I known any breast cancer sufferers well (other than a current client) for example – however, I'm also aware that this is unlikely to remain the case as the statistics suggest that either I, or someone very close to me, will be affected by breast cancer in the future. In fact, I realise that my husband's gran has survived breast cancer, so my own children may face the same disease one day.

Breast reconstruction as a research topic was only decided upon following further reading and discussion – have I been motivated to choose this as it seemed like a 'safer' topic, with a focus on recovery rather than life-threatening illness? Breast recon is typically studied, in my view, at a distance. I feel it's important to alter that

approach so that women's views are heard – what are they thinking and feeling??? If I only ask about what I want to know I won't find out... This provides justification for the research.

20.03.08

Attended 1st support group meeting. Felt very nervous as my 'bit' was preceded by a talk from a chap about to launch a hair salon specialising in wigs. Group were very interested in this worthwhile venture and I suddenly felt as though I wasn't going to be able to justify the relevance of my project! Felt as though I was intruding and imposing my needs upon their time.... However, the group, consisting of a wide age range, were very welcoming and listened with interest to my description of the project. All those who met the inclusion criteria asked to take away a PIS and so now the waiting game begins! How many replies will I get back? How soon will they come? Will I ask the 'right' questions?

24.03.08

Got first reply slip back! At last I can get moving with data collection! Very relieved, but also a bit scared... my role in the data is vital, but I must be careful not to shape the interviews too much but instead let them evolve naturally.

03.04.08

My first interviews today. I'm surprised to say that I really feel as though it's made the research come alive for me! Hearing about women's experiences from their own mouths seems to make the topic more real. I was also surprised by the lack of upset, especially with the participant who reported that she now has a recurrence of cancer, having had 5 years in remission. I was struck by her ability to view her reconstruction surgery as positive... in fact her ability to be positive at all! Yet here she was, trying to help me understand what her experience had been like. The next interview was similarly upbeat, though happily has had no recurrence of the disease.

One interview was delayed recon, the other immediate – much more difficult to get at the impact of reconstruction in the latter case as she had nothing to compare to, having not had the experience of no breast...

Have started on transcribing and initial coding – very sore hands!

10.04.08

More interviews. Have now spoken with both older and younger women. There appears to be a perceived difference in the need for surgery depending upon the age of the patient, i.e. younger women have greater need, older women have less and so sometimes have to fight harder, or endure more difficulties... This does not seem to be a good state of affairs – not only do these women have to battle their cancer, but also the system, or maybe just certain individuals within it...?

Coding is resulting in lots of initial categories!!! Some early themes are definitely apparent though – normality is a big one, both in terms of how the women look to

others, and what the recon allows them to do. Lots of discussion about prostheses being awkward and impacting upon clothing choice. Also children being mentioned quite a lot, but connection to recon seems a bit vague...

13.04.08

Few interviewees have discussed the role of recon in their intimate relationships... I initially thought that this might develop into a theme, but the majority are not bringing it up. I suspect if I were to ask directly about it, they would have lots to say and recon would have a clear and important role – but I don't want to influence the course of the interview... Think I will leave it to them – I ask about the impact upon family and their views, so that would provide an opener if they want to discuss sexual issues with their husband/partner...

18.04.08

Reconstruction = survivor, going to live, not sick anymore, normal again

Confidence re: appearance

Impact of recon/area of difference made to... dependent on the effect of breast cancer diagnosis, so different for each individual...

Mediated by...

Gives back control...

Self-worth...?

05.05.08

Interview Number 7 today. Afterwards, the participant was keen to show me a DVD of a cancer charity fashion show she'd been involved in last year. Although I didn't really have the time, I began to feel myself immersed in the occasion, especially as I recognised several other participants. The participant told me that without breast reconstruction, she would not have been able to take part in the show, but she was so glad that she had..... cancer experience brings these women together, reconstruction allows them to feel full of confidence and vigour.

01.06.08

10th interview has been completed and I think data collection is complete!!! Haven't written in research diary for ages – just been too busy with transcribing and coding... core category is revolving around normality, and recon's role in letting women feel like themselves again. Now feels like the same themes are reappearing, rather than new info being found.... More interviews would possibly further develop the employment, parenting and image as sick person categories, but the time just isn't available. Can recommend this for future research.

12.06.08

Focus group with staff today – in agreement with majority of categories, but doubtful of a few, e.g. recon's role in sense of survival etc, the more symbolic meanings...

Group felt unable to comment on role in employment – not thought about it before, or discussed with patients. Keen to emphasise individual choice...